

The only charity in the UK wholly  
dedicated to the defeat of lung cancer

# Explaining variations in Lung Cancer in England



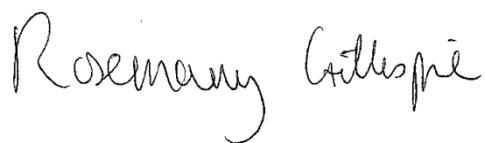
## Foreword

Despite recent advances, lung cancer remains a devastating disease and the most common cause of cancer death in England. International comparisons show that the chance of surviving lung cancer in England is below that in other comparable countries.

With the publication of a number of recent reports, it is clear that lung cancer is characterised by a massive amount of geographical variation, both in terms of patient survival and patient access to care and treatment. We therefore commissioned MHP Health Mandate to compile this report, pulling various data sources together, in order to map a picture of lung cancer across England.

This report is intended as a tool to inform all those with an interest in commissioning and providing lung cancer services. For, in bringing those areas with poorer service and outcomes up to the standard of the best, the lung cancer patient experience will be improved and lives will be saved.

Dr Rosemary Gillespie, Chief Executive



Dr Jesme Fox, Medical Director



July 2011

## Summary of key findings

- Socio-economic disadvantage does not influence survival or access to surgery but does correlate with a decreased use of chemotherapy<sup>1</sup>
- The UK has the worst one and five year survival rate for lung cancer compared to other equivalent countries, Australia, Canada, Norway, Sweden, and Denmark<sup>2</sup>
- There is an almost three-fold variation in lung cancer incidence and mortality across England<sup>3</sup>
- The correlation between lung cancer incidence and mortality shows that most lung cancers are diagnosed at a stage where they are no longer amenable to curative treatment<sup>4</sup>
- Lung cancer has, by far, the worst one year survival rate out of the 'big four' cancers with only 30% of lung cancer patients alive one year post diagnosis compared to 96% of people with breast cancer, 93% of people with prostate cancer and 72% of people with bowel cancer<sup>5, 6, 7, 8</sup>
- Patients with breast cancer are more than three times more likely to survive one year post diagnosis than patients with lung cancer<sup>9, 10</sup>
- One third of lung cancer patients reported that they saw their GP three times or more before being referred to hospital for suspected cancer and only patients with rare cancers reported a worse experience<sup>11</sup>
- More than one third of lung cancers were diagnosed following an emergency admission<sup>12</sup>
- Only 8.9% of patients diagnosed through an emergency admission survived one year post diagnosis<sup>13</sup>
- A lung cancer patient who is admitted to hospital as an emergency will spend, on average, almost twice as long in hospital as a patient whose admission is planned<sup>14</sup>
- There is a three-fold variation in the average number of bed days for an emergency admission between the best and worst performing PCT's<sup>15</sup>
- Eight PCTs had an average elective length of stay of 10 or more bed days<sup>16</sup>
- Lung cancer patients are more than twice as likely to receive active cancer treatment if they are seen by a lung cancer nurse specialist<sup>17</sup>
- More than one third of NHS trusts fail on the National Lung Cancer Audit recommendation that over 80% of lung cancer patients should be seen by a lung cancer nurse specialist<sup>18</sup>
- The National Lung Cancer Audit 2010 found that there is a four-fold variation in the rate of surgery for lung cancer patients across England<sup>19</sup>
- Patients diagnosed with stage III breast cancer are more likely to survive five years post diagnosis than lung cancer patients diagnosed at stage I<sup>20</sup>

- One fifth of cancer networks spent less on lung cancer during 2009-10 compared to 2008-09<sup>21</sup>
- More than 15% of PCTs increased their spending by more than 45% during 2009-10 compared to 2008-09<sup>22</sup>
- One quarter of all lung cancer spending is used on inpatient activity for patients who have presented as an emergency<sup>23</sup>

## Recommendations

1. There is a need to raise awareness of lung cancer symptoms amongst GP, pharmacists, stop-smoking professionals and the general public, in order to increase the chances of early detection in lung cancer.
2. The Roy Castle Lung Cancer Foundation welcomes the commitment from the Department of Health to investigate survival differences between countries through a new international benchmarking project, *International Cancer Benchmarking Partnership*<sup>24</sup>, over the next 18 months. However, we urge the Government, healthcare providers and commissioners to act on this research and put strategies in place to bring lung cancer survival up to be in line with other comparable countries.
3. In future, the National Cancer Patient Experience Survey should be designed in such a way that it captures the experiences of the most ill lung cancer patients in order to give a more complete picture of the experience of all patients with the disease.
4. In order to improve the training and expertise in primary care, The Roy Castle Lung Cancer Foundation has been campaigning for GPs to be encouraged to undertake a significant event review in their practice for every diagnosis of cancer to encourage practice-based learning. *Improving Outcomes: A Strategy for Cancer* stated that the Department of Health is assessing how audits can be integrated into GP training, appraisal and revalidation<sup>25</sup>. We would like to see this practice-based learning become a routine part of General Practice.
5. We urge the eight PCTs whose average elective length of stay for lung cancer is 10 days or over to consider why this is so much higher than the majority of other PCTs and put measures in place to reduce this.
6. In order to help reduce the length of stay for patients admitted as an emergency admission we urge providers to act upon the recommendations made in the National Chemotherapy Advisory Group report *Chemotherapy Services in England: Ensuring quality and safety*<sup>26</sup>. In particular, it is critically important that all hospitals with A&E departments should establish an acute oncology service to improve the management of cancer patients admitted as an emergency.
7. We call on the government to ensure that all patients have equitable access to the best treatment and care, including access to specialist nurses at all times.

8. We urge trusts and commissioners to scrutinise the results of the National Lung Cancer Audit 2010 to determine and act upon areas where improvements need to be made.
9. There is a significant time lag in collecting, analysing and publishing many cancer datasets. As part of the Government's information revolution we hope that data collection can be streamlined, making it as near to 'real-time' as possible.
10. We welcome the Government's drive to improve both one and five year survival for lung cancer through inclusion of these measures in the *The NHS Outcomes Framework 2011/12*<sup>27</sup>, as an improvement area in domain one "*preventing people from dying prematurely*". We hope that this ongoing scrutiny of outcomes in lung cancer will lead to much needed improvements in outcomes for patients.
11. The trends on changes in spending require further investigation at a local level. For those PCTs that have made dramatic changes to their spending on lung cancer, we recommend that local investigation should be undertaken to establish the reasons behind the change and whether any assessment has been made of how this has affected outcomes for people with lung cancer.
12. We believe that patients and carers should be given more support to self-manage their condition so that they know who to contact when assistance is needed and in order to avoid unnecessary emergency admissions. Additionally, patients should have a clearly defined care plan based on their individual needs which sets out reasons for admission to hospital.

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## 1. Introduction

The Roy Castle Lung Cancer Foundation was founded in 1990 and is the only charity in the UK wholly dedicated to defeating lung cancer. We work to:

- Support and fund research into the early detection and prevention of lung cancer
- Provide support for people affected by lung cancer through information, advice and advocacy, and through raising awareness of the disease
- Raise awareness of the harm caused by tobacco and build capacity to reduce and prevent the harm caused by smoking through our FagEnds stop smoking services
- Campaign for more research and for better care and treatment for people affected by lung cancer, and for strong anti-tobacco measures to support reductions in smoking prevalence

Lung cancer is the UK's most common cause of cancer death for both men and women, responsible for nearly a quarter (24%) of all male cancer deaths and a fifth (21%) of all female cancer deaths<sup>28</sup>. Each year around 40,000 people are diagnosed with lung cancer in the UK (more than 100 people each day, or more than one person dying every 15 minutes)<sup>29</sup>.

Despite this, awareness of the signs and symptoms of lung cancer is low and more than two thirds of patients are diagnosed at a stage when curative treatment is no longer an option. Once patients are diagnosed with lung cancer there are significant variations around the country in outcomes, treatment, care and patient experience.

We have therefore undertaken this piece of work to look closely at the data which exists on lung cancer and highlight new statistics showing the poor survival rates for lung cancer in England and to shine a spotlight on the variations and inequalities which exist.

We have also made some recommendations on how policy can be improved to deliver better quality lung cancer services. We hope that these recommendations will be useful to a wide range of stakeholders including commissioners, service providers and policymakers.

For more information about our work please contact:

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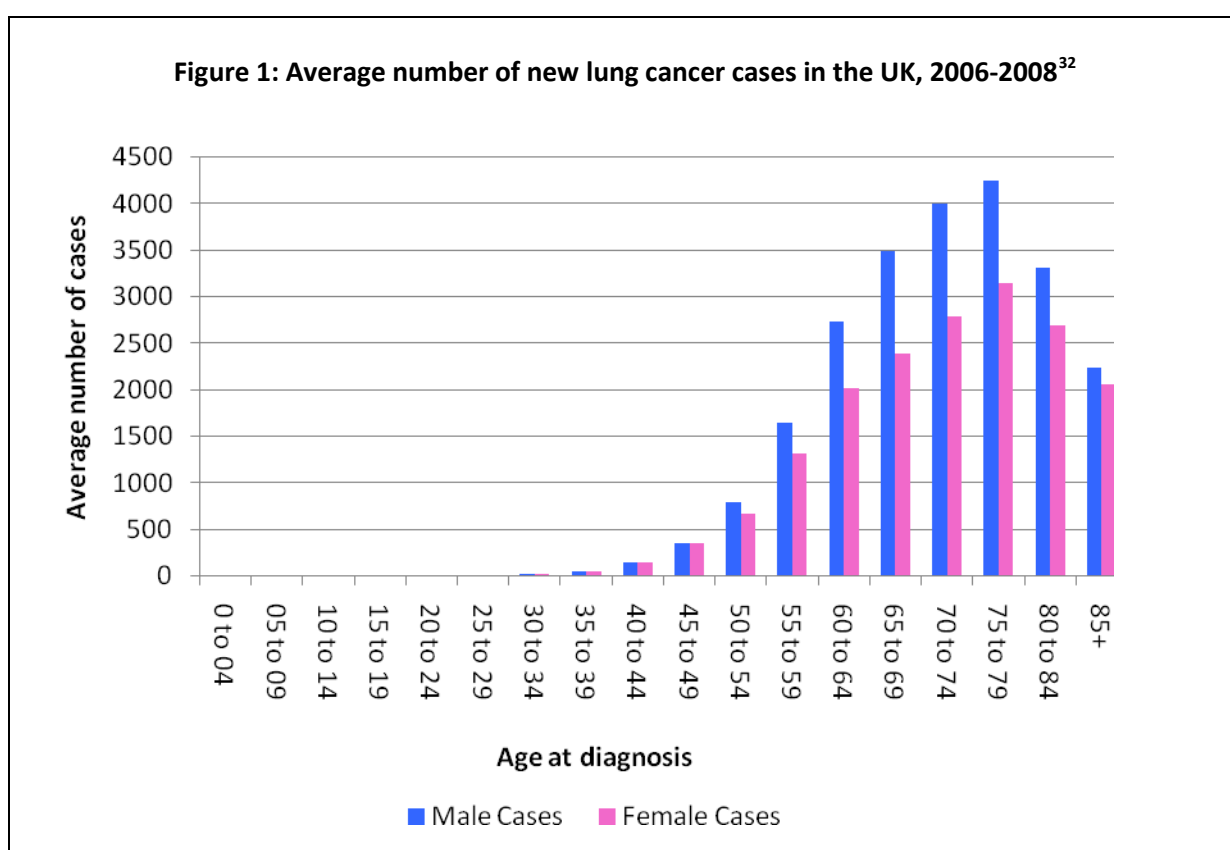
**Or visit our website [www.roycastle.org](http://www.roycastle.org)**

## 2. Risk Factors

There are a number of risk factors for lung cancer including age, deprivation and lifestyle including smoking.

### Age

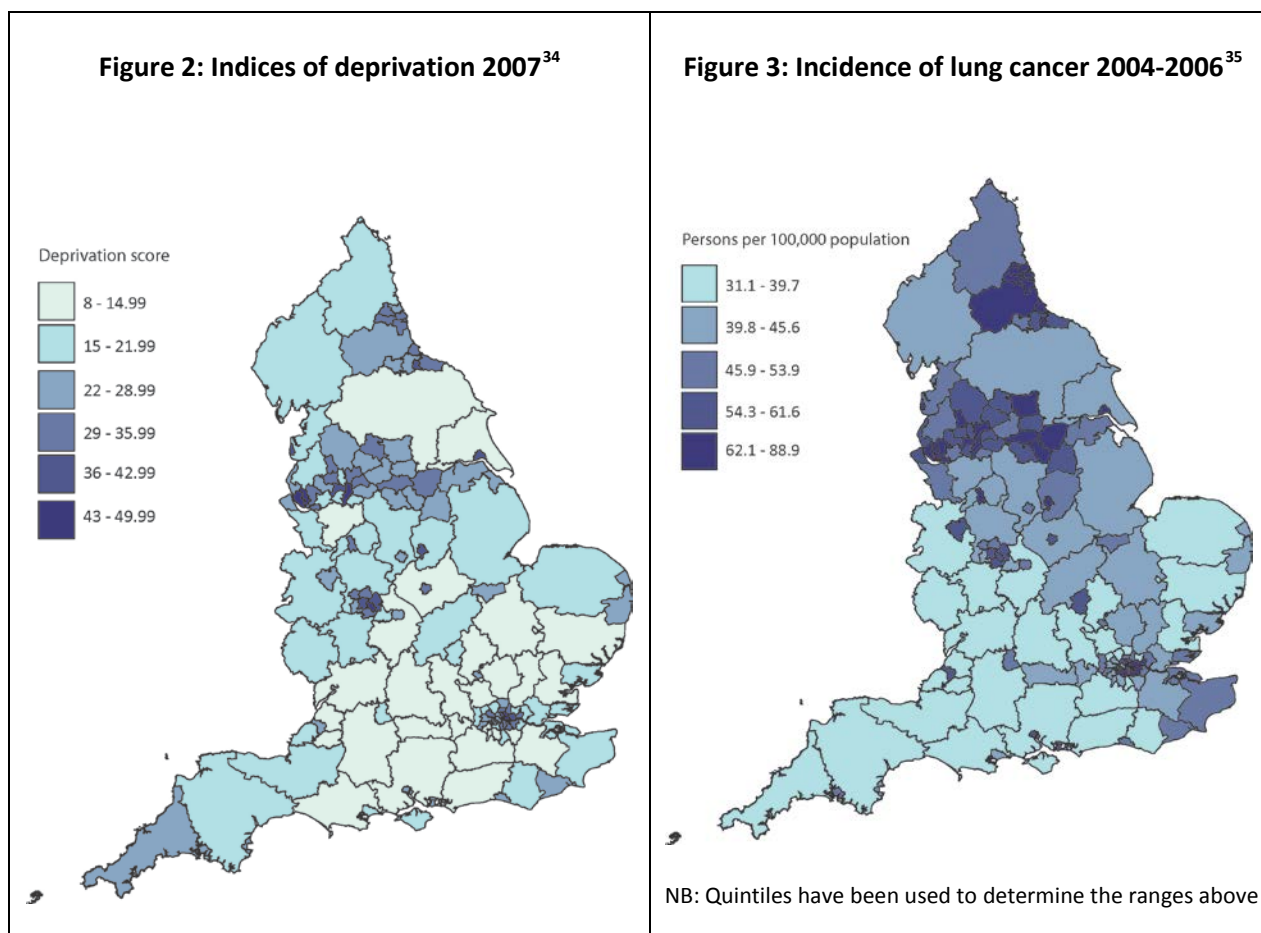
As the population ages and average life expectancy increases, cancer incidence is likely to rise. The prevalence of lung cancer increases with age, with the disease most likely to be diagnosed in people over 60 and with a peak of diagnoses in the 75 to 79 age bracket<sup>30</sup>, as demonstrated in Figure 1. Men are more likely to get lung cancer, but the disease is significant in women too<sup>31</sup>.



### Deprivation

Lung cancer incidence and mortality rates are strongly associated with deprivation<sup>33</sup>. Figures 2 and 3 below, show the geographical correlation between higher incidence of lung cancer and a higher score on the indices of deprivation.





High levels of deprivation exist in urban hubs, reflecting many of the areas which have high incidence rates for lung cancer. This may, in part, be explained by the historical presence of heavy industry which can be linked to lung cancer and due to higher smoking rates in cities.

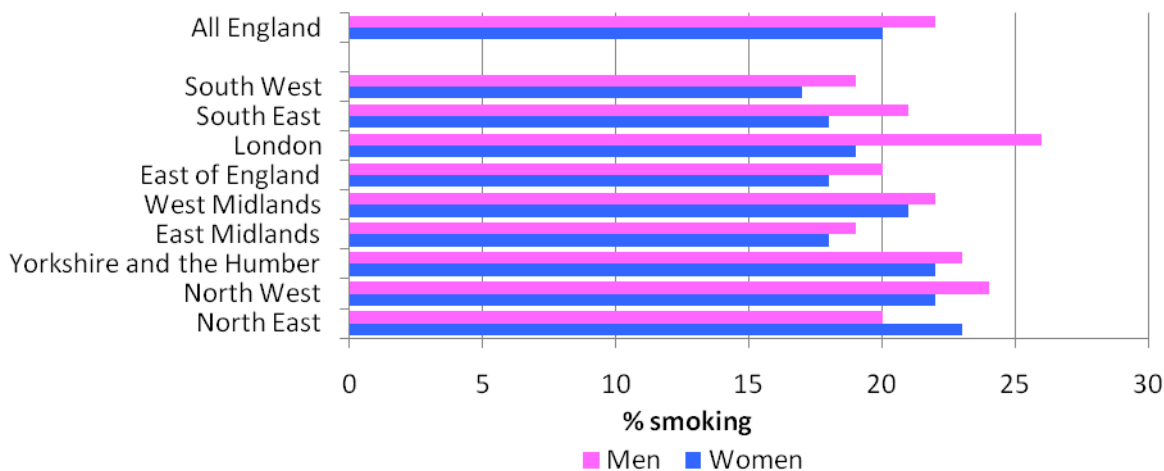
However, it is interesting to note that recent research has found that socio-economic disadvantage does not influence survival or access to surgery but does correlate with a decreased use of chemotherapy<sup>36</sup>.

### Smoking

Tobacco remains the single biggest lifestyle risk factor, accounting for nearly nine out of ten lung cancers<sup>37</sup>. On average, a lifetime smoker is 20 times more likely to develop lung cancer compared with a lifetime non-smoker<sup>38</sup>.

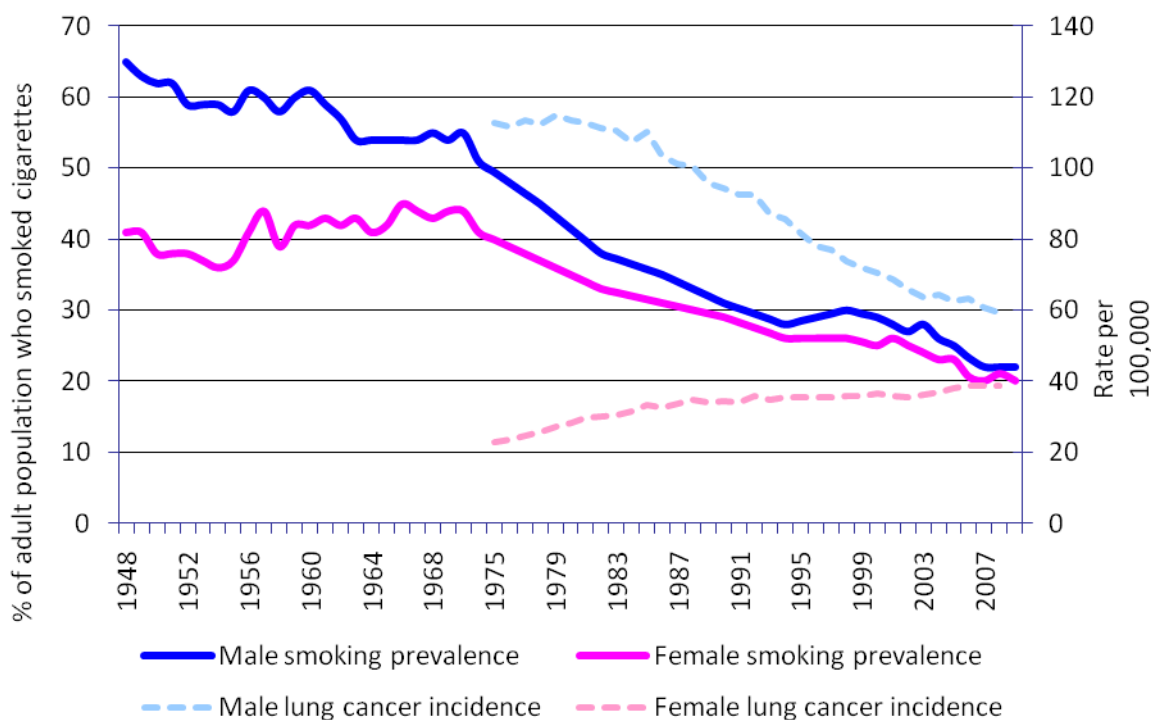
The geographical variation in smoking prevalence in England reflects incidence rates for lung cancer, with highest smoking prevalence in the North West and lowest in the South West, as shown in Figure 4<sup>39</sup>.

**Figure 4: Prevalence of cigarette smoking by sex, England and Government Office Regions, 2009<sup>40</sup>**



The higher incidence of lung cancer in men reflects past patterns of smoking prevalence between the sexes, as shown in Figure 5<sup>41</sup>. However, despite the falling rates of smoking prevalence, the number of adults in Britain who currently smoke cigarettes is still high, at around 10 million<sup>42</sup>.

**Figure 5: Lung cancer incidence and smoking trends, Great Britain, by sex, 1948-2009<sup>43</sup>**



The strength of evidence showing that non-smokers are put at risk of lung cancer and other health issues by exposure to other people's smoke<sup>44</sup>, and a campaign which the Roy Castle Lung Cancer

Foundation were involved in, led to the introduction of legislation in the UK in 2007, making enclosed public places and workplaces smoke-free<sup>45</sup>. To further this success we call on the government to commit to the provision of high quality stop smoking services.

**There is a need to raise awareness of lung cancer symptoms amongst GP, pharmacists, stop-smoking professionals and the general public, in order to increase the chances of early detection in lung cancer.**

### 3.The international context

Lung cancer incidence rates and outcomes vary across the world. Disparities in outcomes suggest that there are a significant number of avoidable deaths in lung cancer. This is a particular problem in the UK as we perform worst on both one and five year survival when compared to other similar countries (Australia, Canada, Denmark, Norway and Sweden)<sup>46</sup>. This poor performance is shown in figures 6 and 7 below.

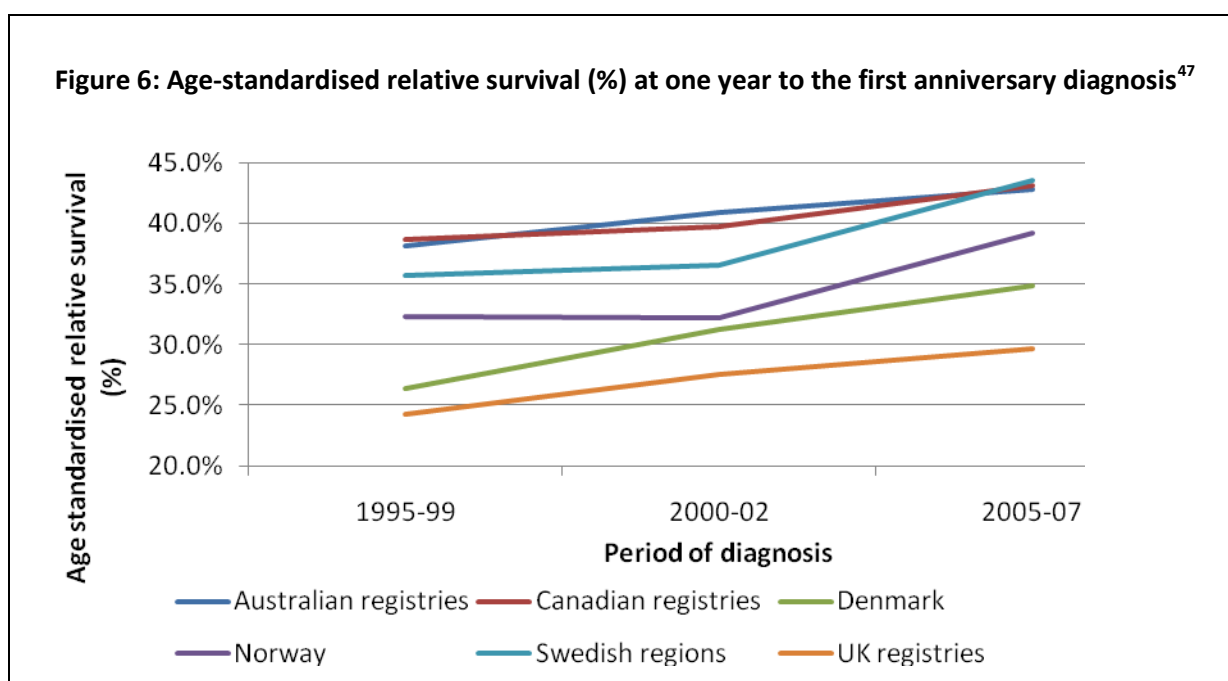
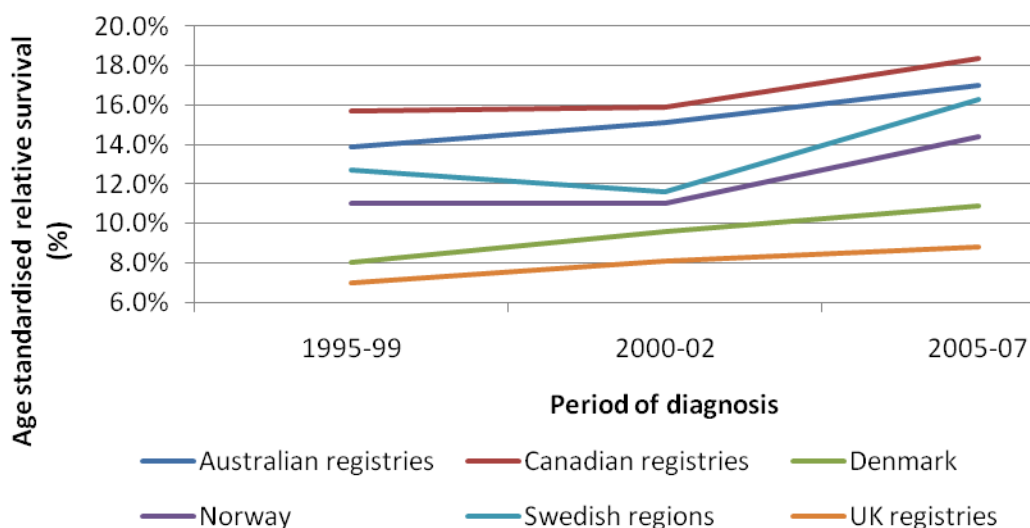


Figure 7: Age-standardised relative survival (%) at five years to the first anniversary diagnosis<sup>48</sup>



Across all of the diagnosis periods, both one and five year lung cancer survival were lower in Denmark and the UK than the other comparable countries considered in the research<sup>49</sup>. This suggests that late diagnosis is a problem in both countries. One and five year survival have improved more rapidly in Denmark since 2000-02 than in the UK, leaving us lagging further behind on outcomes than other comparable countries<sup>50</sup>. Additionally, the UK's poor performance may be a result of high incidence rates of lung cancer due to the early spread of the smoking habit.

**The Roy Castle Lung Cancer Foundation welcomes the commitment from the Department of Health to investigate survival differences between countries through a new international benchmarking project, *International Cancer Benchmarking Partnership*<sup>51</sup>, over the next 18 months. However, we urge the Government, healthcare providers and commissioners to act on this research and put strategies in place to bring lung cancer survival up to be in line with other comparable countries.**

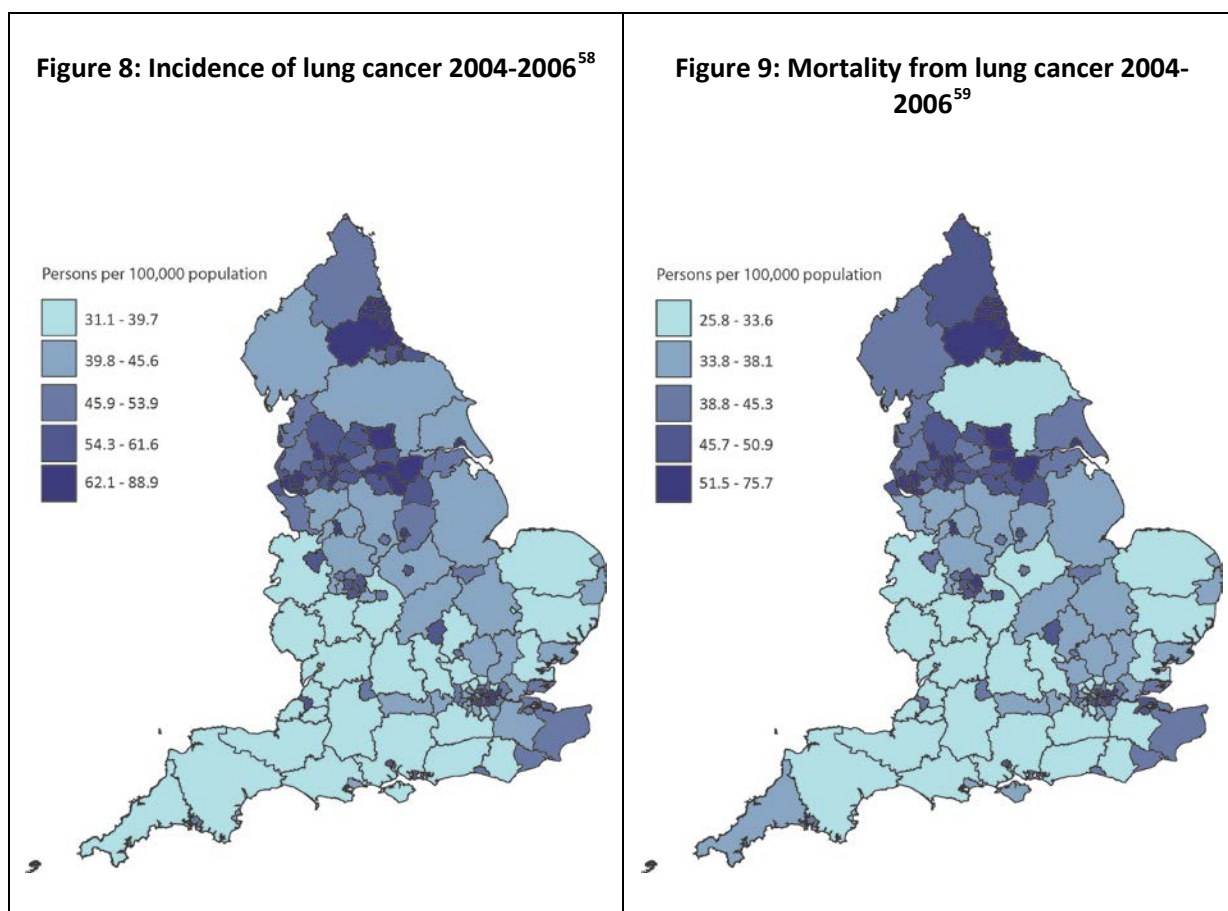
## 4. Incidence and mortality

Due to the poor prognosis of lung cancer, patterns of incidence and mortality across England are very similar. Figures 8 and 9 show that there is a clear north–south divide in both incidence and mortality, with the exception of London which, though in the South, has a high incidence of, and mortality from, lung cancer<sup>52, 53</sup>.

Manchester PCT and Liverpool PCT both have the highest incidence rate of lung cancer at 88.9 people per 100,000 population<sup>54</sup>. Liverpool PCT also has the highest mortality rate from lung cancer at 75.7 people per 100,000 population<sup>55</sup>.

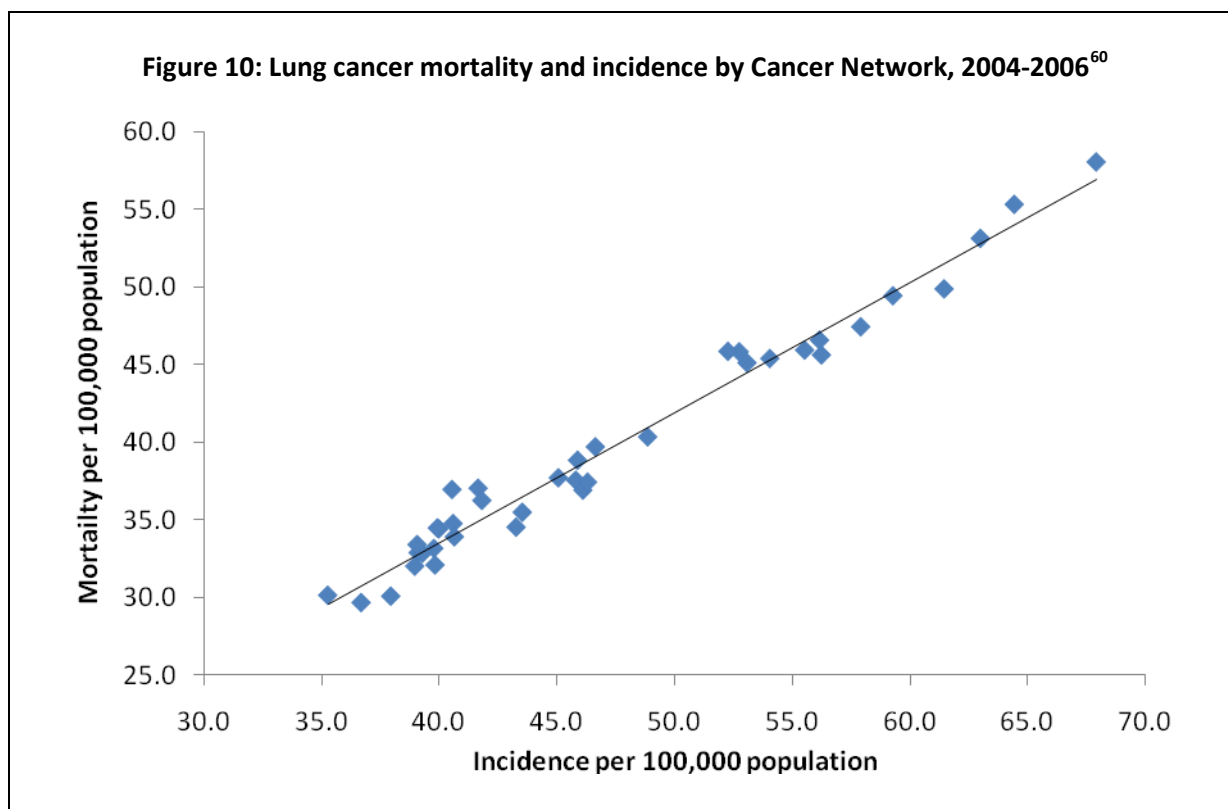
Herefordshire PCT has the lowest incidence and mortality with rates of 31.1 and 25.8 people per 100,000 population respectively<sup>56, 57</sup>.

**There is almost a three-fold variation in both incidence and mortality of lung cancer across England.**



NB: Quintiles have been used to determine the ranges above

Demonstrating this relationship further, Figure 10 shows that there is a strong correlation between incidence and mortality for lung cancer at the cancer network level.



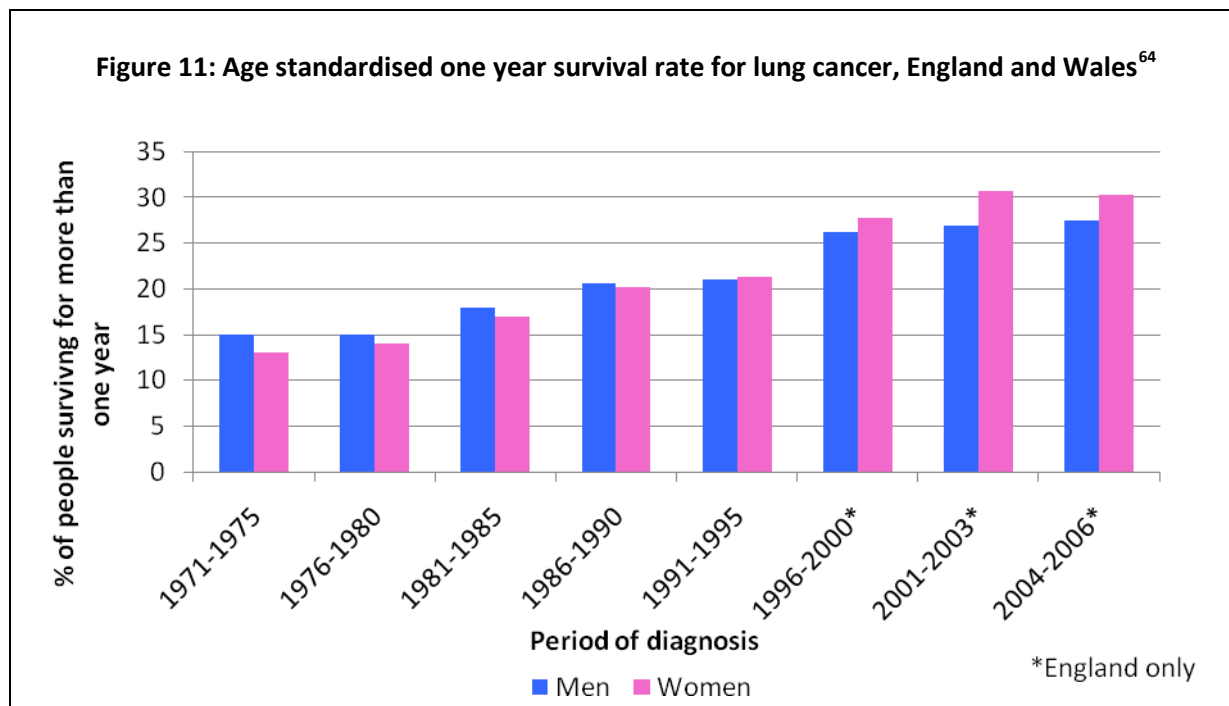
The North East Cancer Network had both the highest incidence and mortality from lung cancer at 67.9 per 100,000 persons and 58.0 per 100,000 persons respectively during the last year when comparable data is available (2004-06)<sup>61</sup>. Three Counties Cancer Network had the lowest incidence, and Surrey, West Sussex and Hampshire Cancer Network had the lowest mortality from lung cancer during this period<sup>62</sup>.

The graph above shows the very strong correlation that exists between mortality and incidence. The strength of this correlation is due to the fact that lung cancers are diagnosed at a stage where they are no longer amenable to curative treatment.

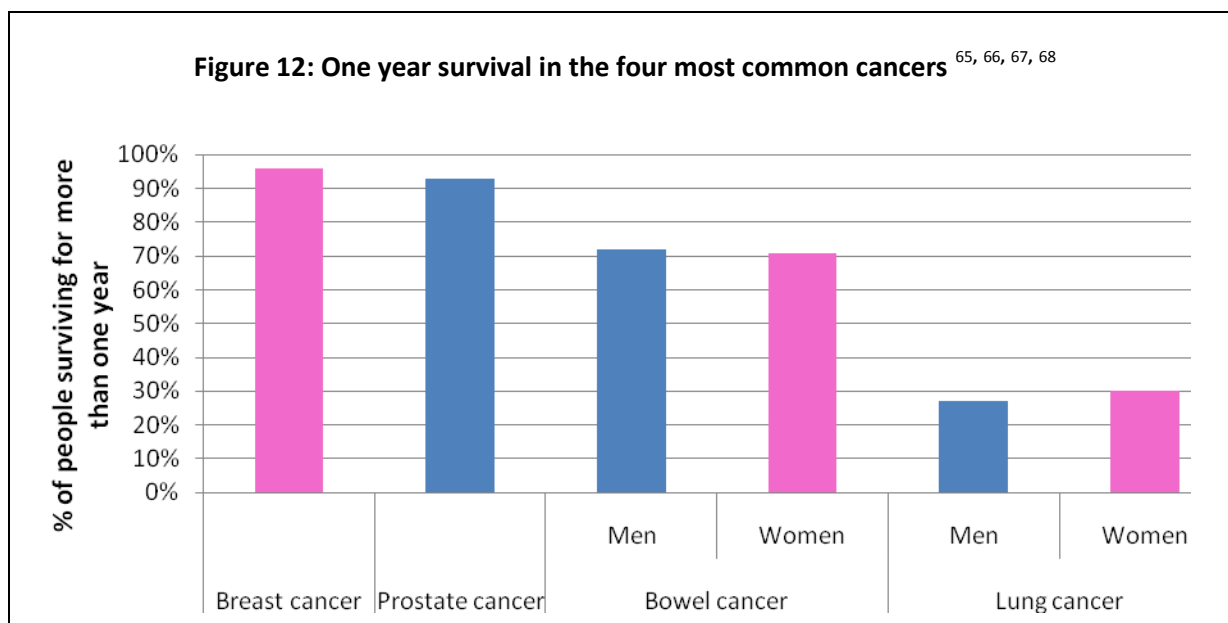
## 5. Diagnosis

One year survival rates are commonly used as a proxy for late diagnosis, as generally the later the diagnosis, the greater the likelihood of a person with cancer not surviving for one year.

Figure 11 shows that although there has been a marked improvement in one year survival since the 1970s, still only 27% of men and 30% of women are alive one year after a diagnosis of lung cancer, for the last period that data are available<sup>63</sup>.



To put this in context, one year survival in the other big four cancers are as follows:



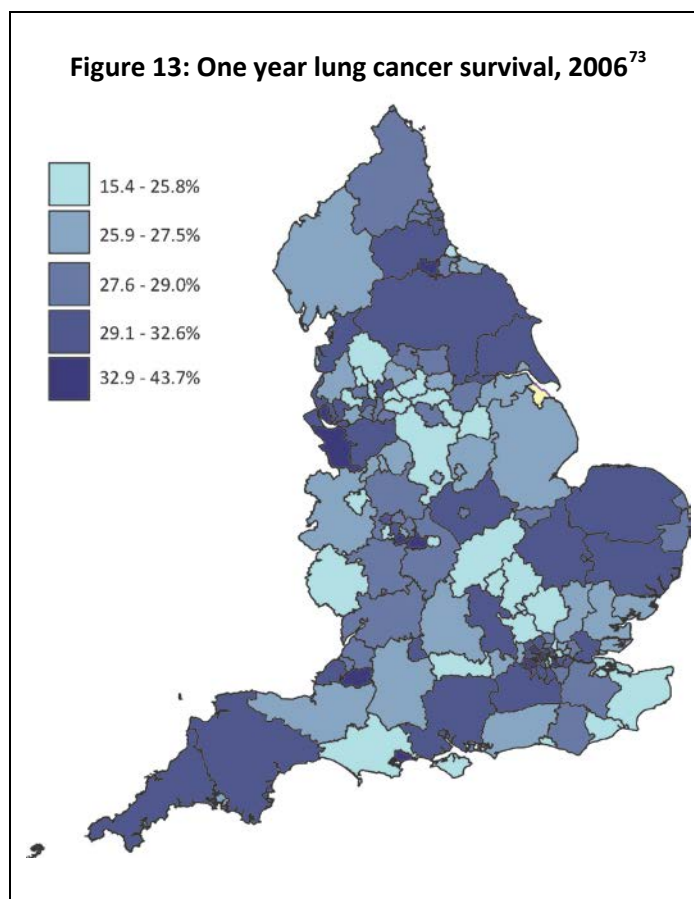
In breast cancer, one year survival is 96%<sup>69</sup>, more than three times higher than the survival of both men and women with lung cancer<sup>70</sup>.

**“Patients with breast cancer are more than three times more likely to survive one-year post diagnosis than patients with lung cancer.”**

Looking at how the one year survival rate varies across the country shows some interesting patterns, as illustrated in Figure 13. For example, despite having both the lowest incidence and mortality rate per 100,000 of the population of all the PCTs, Herefordshire PCT has the worst one year survival rate at 15.4%<sup>71</sup>. This perhaps demonstrates that, as the condition is not as common in this area as in others, there is a problem with late diagnosis of those people who are unlucky enough to have lung cancer. GPs may be less aware of the signs and symptoms of lung cancer or they might be more reluctant to refer patients on for appropriate diagnostic tests. This could also be a sign that lung cancer services are not so well organised and that patients are not getting access to chemotherapy.

Kensington and Chelsea PCT has the highest one year survival rate at 43.7%<sup>72</sup>. Although this is significantly higher than in other areas, it demonstrates the exceptionally poor prognosis for patients with lung cancer as more than half of all patients do not survive one year post-diagnosis even in the best performing area.





NB: Quintiles have been used to determine the ranges above

In order to determine whether late diagnosis really is a driver for poor patient outcomes, a number of new datasets are becoming available giving an insight into the experience and outcomes of cancer patients which puts much of the survival information into context.

The National Cancer Patient Experience Survey 2010, collected insights into the care experienced by cancer patients across England who were treated as day cases or inpatients during the first three months of 2010. The 2010 survey builds on a previous survey undertaken in 2000 and a smaller survey undertaken in 2004.

In order to put the survey in context, it is important to note that many lung cancer patients with the most serious cases of the disease would not have been in a position to complete the survey and therefore it is likely that respondents with lung cancer had their cancer identified at an earlier stage. The results of the survey are therefore probably biased for lung cancer.

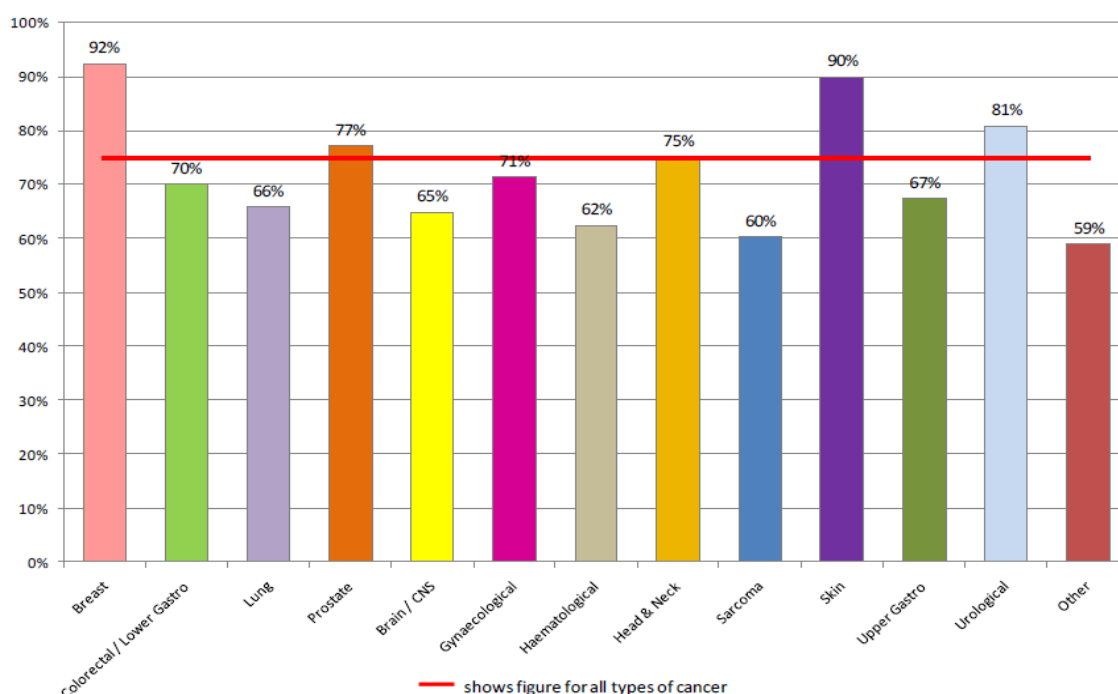
**In future, the National Cancer Patient Experience Survey should be designed in such a way that it captures the experiences of the most ill lung cancer patients in order to give a more complete picture of**

**“ One third of lung cancer patients reported that they saw their GP three times or more before being referred to hospital for suspected cancer. ”**

**the experience of all patients with the disease.**

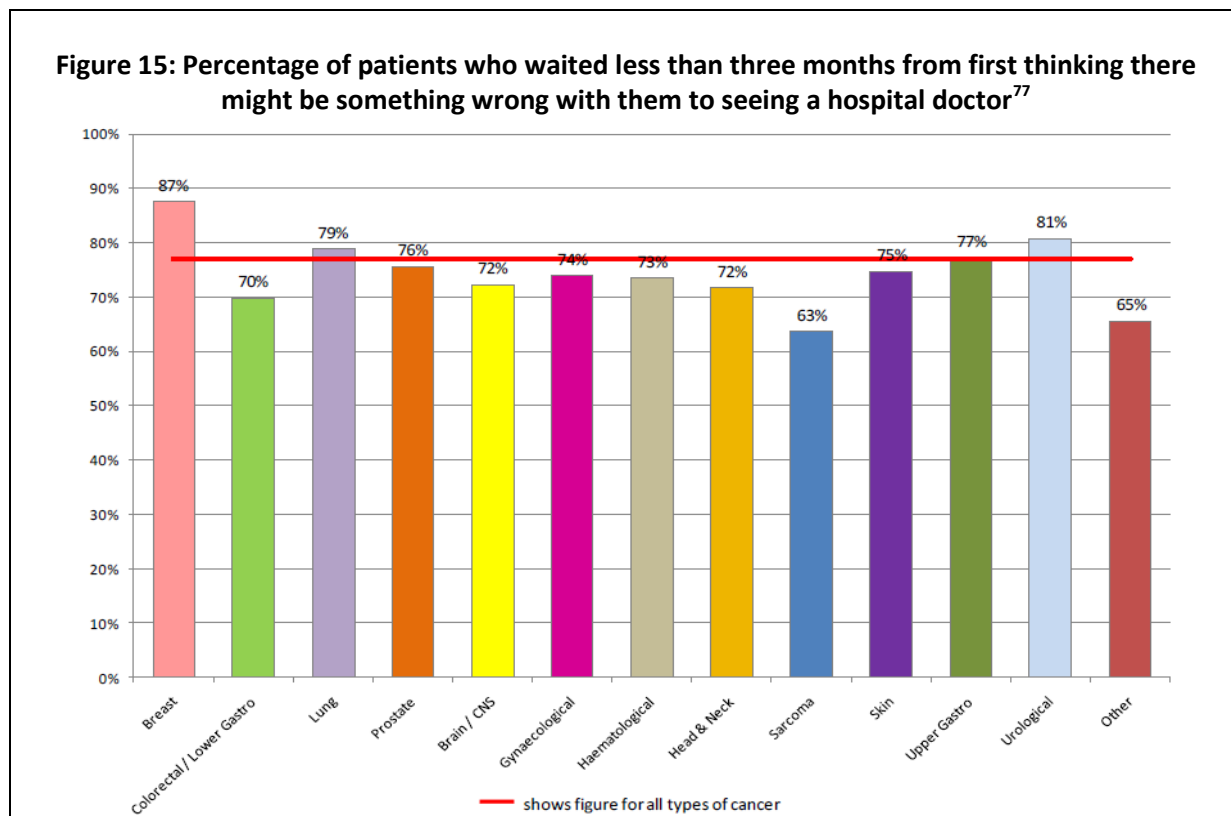
Despite these limitations, some interesting insights into the experience of lung cancer patients were collected. For example, the survey confirmed that (of those patients who took part), one third of lung cancer patients reported that they saw their GP three or more times about the health problem caused by the cancer before being referred to hospital for suspected cancer<sup>74</sup>. It is notable that on average only one quarter of all cancer patients reported seeing their GP three or more times before being referred to hospital. In fact, as shown in Figure 14, only patients with rare cancers reported a worse experience in relation to the number of GP appointments they had before being referred to hospital.

**Figure 14: Percentage of patients who saw their GP no more than twice before being referred to hospital with suspected cancer<sup>75</sup>**



As lung cancer is one of the four most common cancers, it is disappointing that there is a delay between patients presenting at their GP surgery and being referred on to hospital. However, we accept that there are potential delays as symptoms are often not specific. GPs are likely to see about one case of lung cancer every year, whereas for some of the rarer cancers they are more likely to see one case in their career.

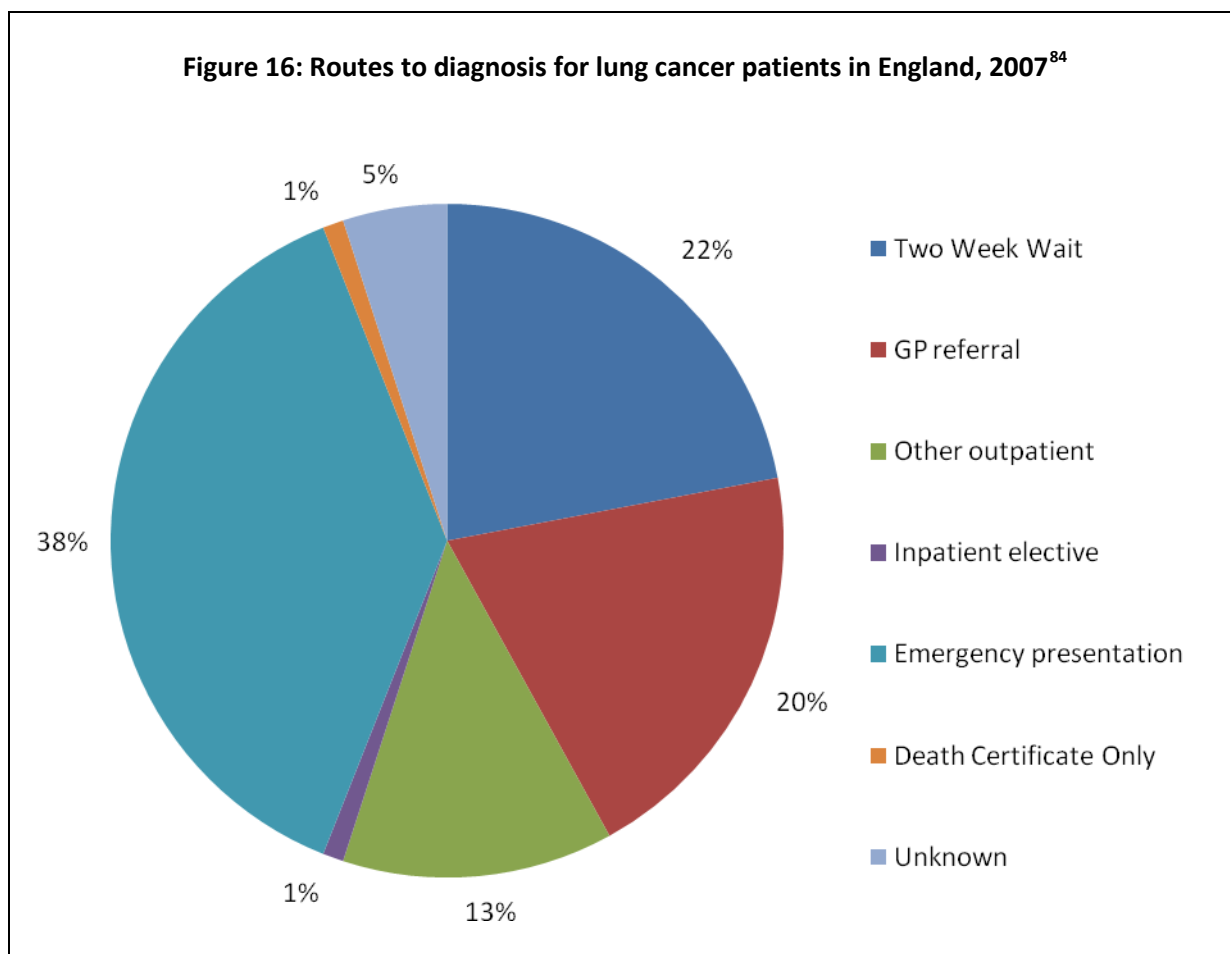
The National Cancer Patient Experience Survey also reports the number of patients who waited less than three months from the point of thinking that there was something wrong with them, to seeing a hospital doctor. 79% of patients with lung cancer who responded to the survey said that they had waited less than three months to first seeing a hospital doctor<sup>76</sup>. This suggests that once a lung cancer patient is in the system and identified as having lung cancer they are likely to move quickly to seeing a secondary care doctor.



In order to improve the training and expertise in primary care, The Roy Castle Lung Cancer Foundation has been campaigning for GPs to be encouraged to undertake a significant event review in their practice for every diagnosis of cancer to encourage practice-based learning. *Improving Outcomes: A Strategy for Cancer* stated that the Department of Health is assessing how audits can be integrated into GP training, appraisal and revalidation<sup>78</sup>. We would like to see this practice-based learning become a routine part of General Practice.

We are also encouraged that, following advice from the Cancer Diagnostics Advisory Board, GPs will now be able to directly refer patients for a chest x-ray in instances where the two week urgent referral pathway is not appropriate but symptoms require further investigation<sup>79</sup>. We are awaiting information to see if this direct access to diagnostic testing makes an impact on the number of patients who are given a chest x-ray.

Looking at the routes that lung cancer patients take to get a diagnosis shows that, despite there being delays in GP referral to hospital, many lung cancers are actually diagnosed as an emergency<sup>80</sup>. More than one third of lung cancers (38%) are diagnosed following an emergency presentation, which is extremely high compared to other cancers<sup>81</sup>. On average, across all cancers, 23% of patients are presenting as emergencies<sup>82</sup>. Interestingly, when breaking down the data by deprivation quintile there is no real difference in the route to diagnosis in each of the deprivation groups<sup>83</sup>.

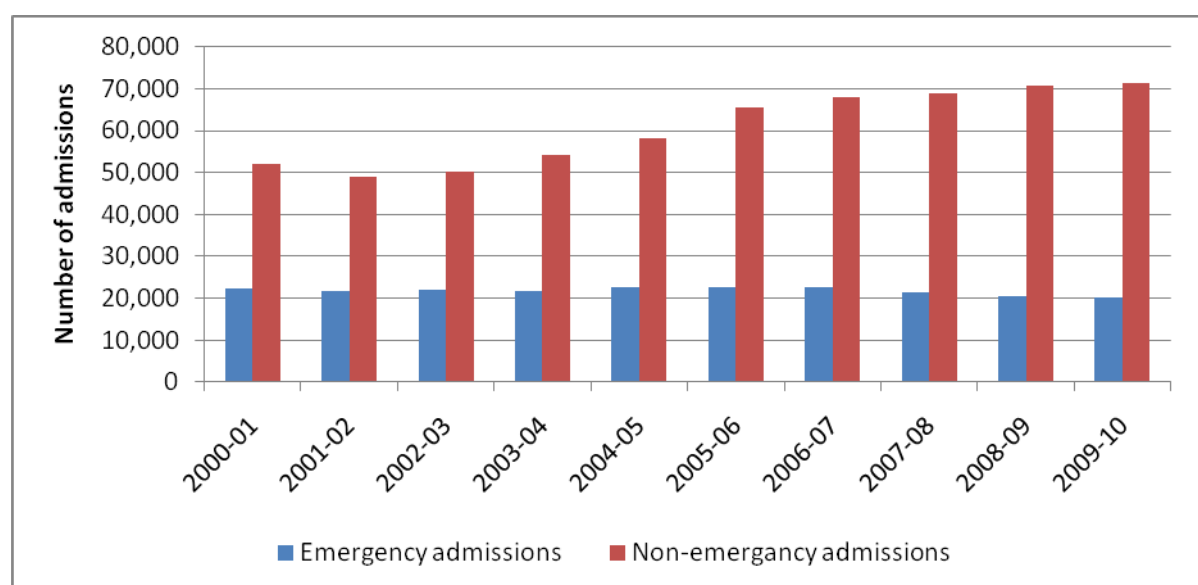


The route to diagnosis has a material association with the survival of patients with lung cancer. In this research, it was found that 39.8% of lung cancer patients diagnosed via a GP referral, the two week wait and other outpatient settings survived one year post-diagnosis. On the other hand, only 8.9% of patients admitted as an emergency survived one year post-diagnosis<sup>85</sup>.

## 6. Admissions and length of stay

Despite the strong push by cancer patients and policymakers to try and ensure that more cancer patients are treated and managed in the community, hospital admissions for lung cancer remain high and are rising.

**Figure 17: Emergency and non-emergency admissions for malignant neoplasms of respiratory & intrathoracic organs<sup>86</sup>**

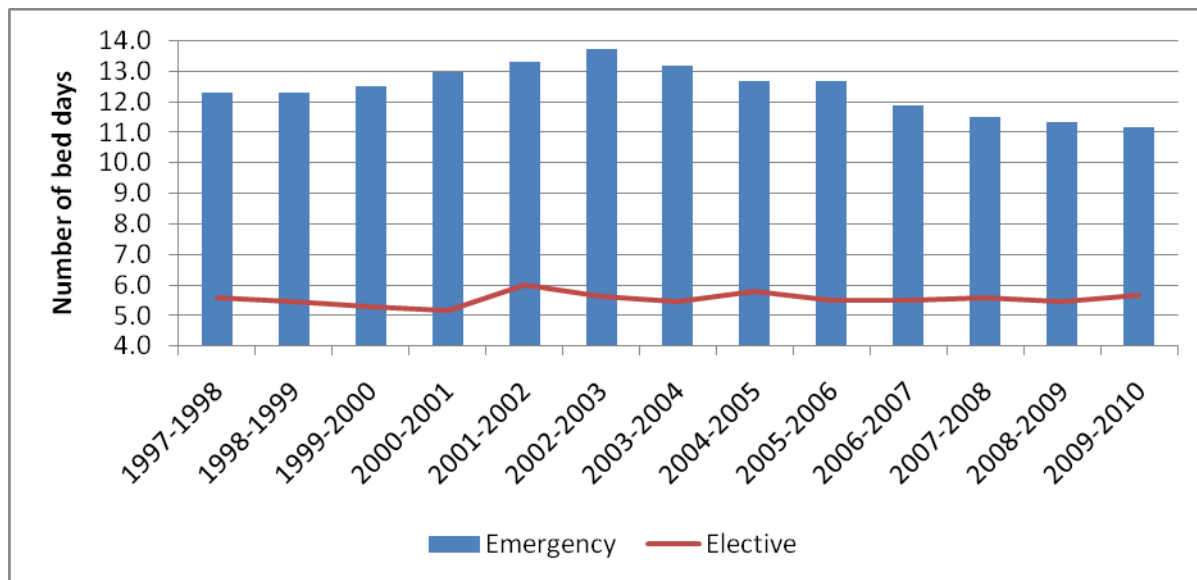


In total, there were 91,627 admissions (emergency and non-emergency) for lung cancer during 2009-10 compared to 70,582 during 2001-02<sup>87</sup>. This represents more than a 20% increase in admissions. It is interesting to note that this increase in admissions was driven almost entirely from additional non-emergency admissions.

The national trends for emergency and non-emergency admissions are interesting, however it is difficult to determine what an appropriate number of admissions should be in any given year. It is therefore more interesting to look at the length of stay for elective and emergency admissions to determine if there is variation across England.

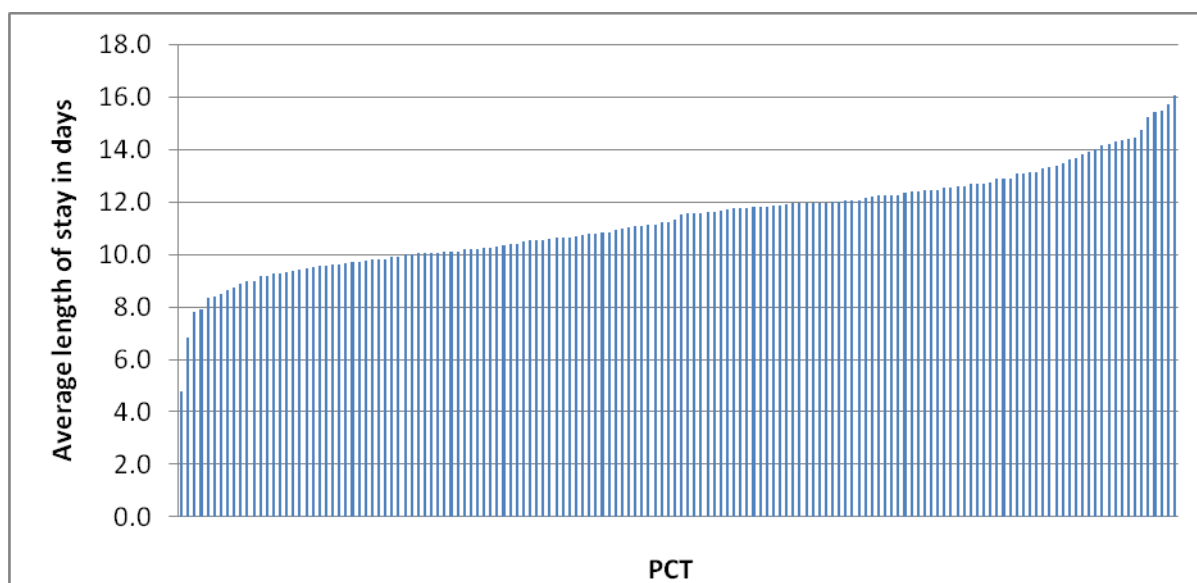
Length of stay following an elective admissions has remained largely static since 1997-98 with the England average ranging between 5.2 and 6.0 bed days<sup>88</sup>. For emergency admissions, however, the length of stay is decreasing<sup>89</sup>. Encouragingly, after a peak in the average length of stay of 13.7 days for an emergency admission in 2002-03 this has steadily decreased over time to 11.2 during 2009-10<sup>90</sup>. Despite this progress, a lung cancer patient admitted as an emergency will still spend, on average, almost twice as long in hospital as a patient whose admission is planned<sup>91</sup>.

**Figure 18: Average length of stay in days for elective and emergency lung cancer admissions, England average<sup>92</sup>**



Within the national picture there are significant local variations in the average length of stay particularly in emergency admissions as shown in Figure 19.

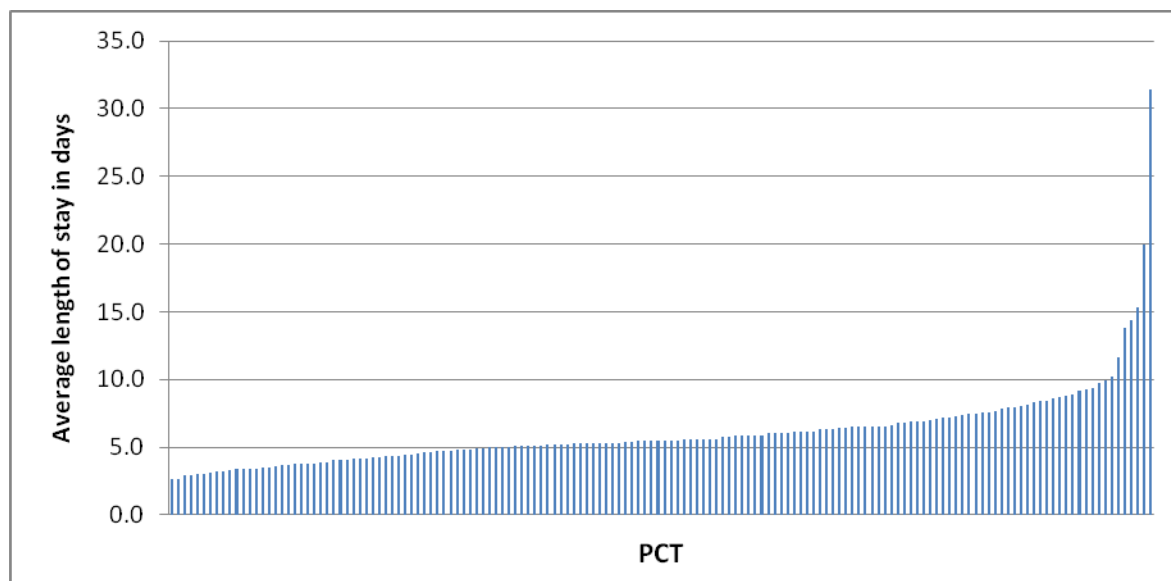
**Figure 19: Average length of stay in days (emergency) for lung cancer patients by PCT, 2009-10<sup>93</sup>**



In 2009-10, the average length of stay in bed days for patients presenting as an emergency across England is 11.4 days<sup>94</sup>. This ranged from an average of 4.8 days in Great Yarmouth and Waveney PCT to 16.1 days in Kensington and Chelsea PCT<sup>95</sup>. This represents more than a three-fold variation in the average number of bed days per finished consultant episode<sup>96</sup> where an emergency admission took place between the best and worst performing PCTs.

There are also variations between PCTs in the average length of stay for an elective admission.

**Figure 20: Average length of stay in days (elective) for lung cancer patients by PCT, 2009-10<sup>97</sup>**



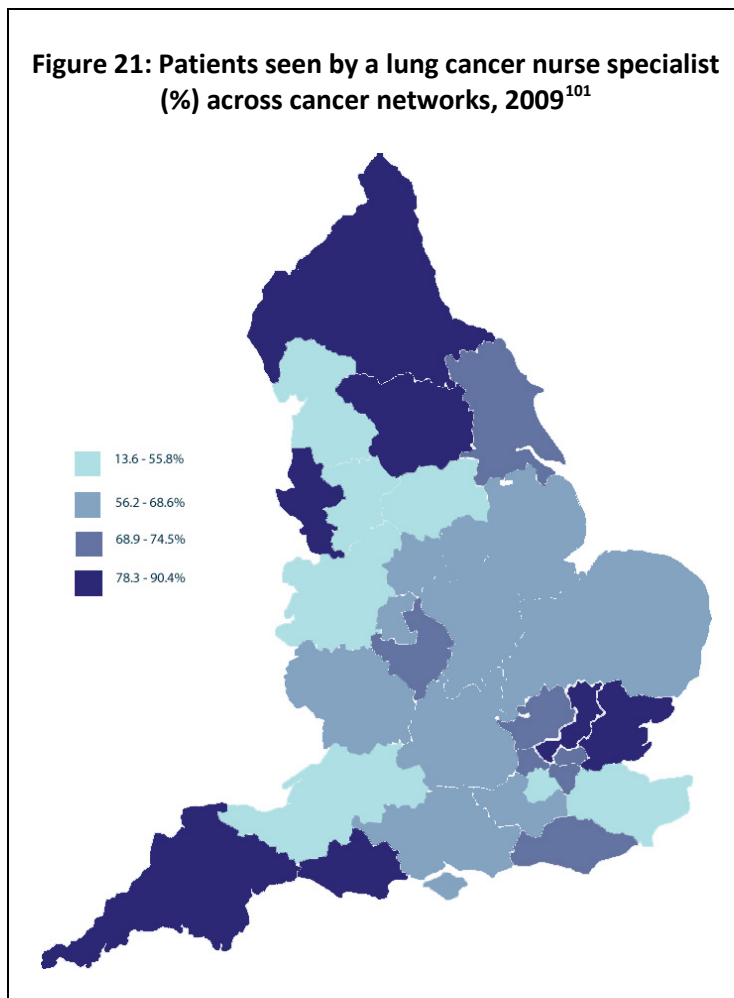
In 2009-10, the average length of stay in bed days for elective lung cancer patients was 6.1 days. This ranges from Bath and North East Somerset PCT where the lowest average number of bed days for an emergency admission stood at 2.6 days, compared to City and Hackney Teaching PCT whose average number of bed days was 31.4<sup>98</sup>. As is clear from Figure 20 there are a number of PCTs who have unusually long lengths of stay for elective patients. Eight PCTs had an average elective stay of 10 or more bed days. Including these eight PCTs in the analysis clearly skews the data.

**We urge the eight PCTs whose average elective length of stay for lung cancer is 10 days or over to consider why this is so much higher than the majority of other PCTs and put measures in place to reduce this.**

**In order to help reduce the length of stay for patients admitted as an emergency admission we urge providers to act upon the recommendations made in the National Chemotherapy Advisory Group report '*Chemotherapy Services in England: Ensuring quality and safety*'<sup>99</sup>. In particular, it is critically important that all hospitals with A&E departments should establish an acute oncology service to improve the management of cancer patients admitted as an emergency.**

## 7. Access to clinical nurse specialists

Since the introduction of the clinical nurse specialist (CNS) role in 1995 there has been an increase in the absolute number of CNSs for lung cancer<sup>100</sup>. However, there are variations in access to lung cancer CNSs across England.

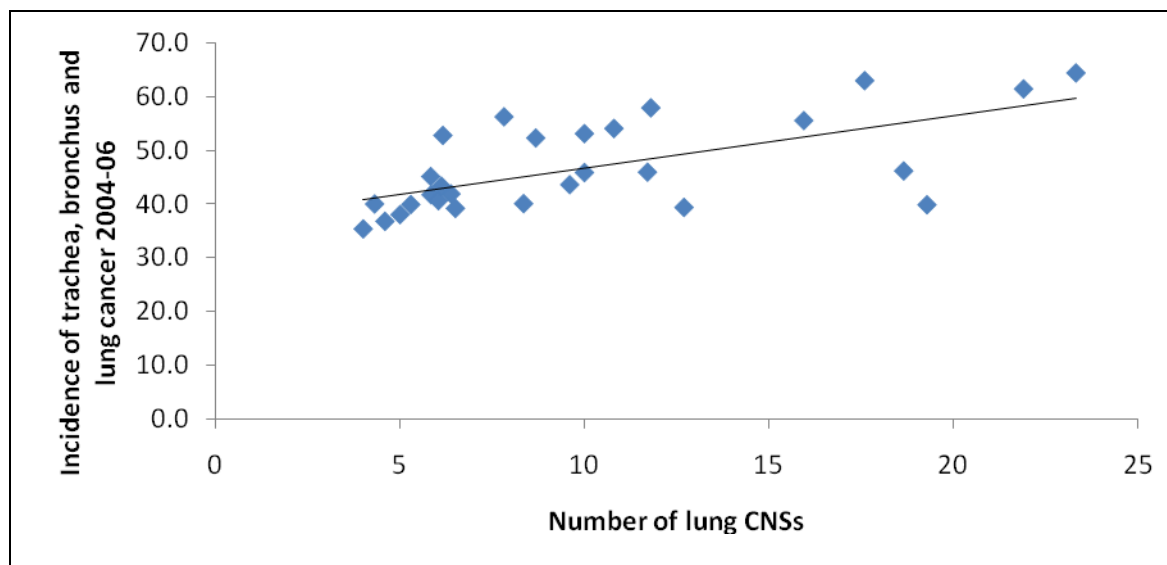


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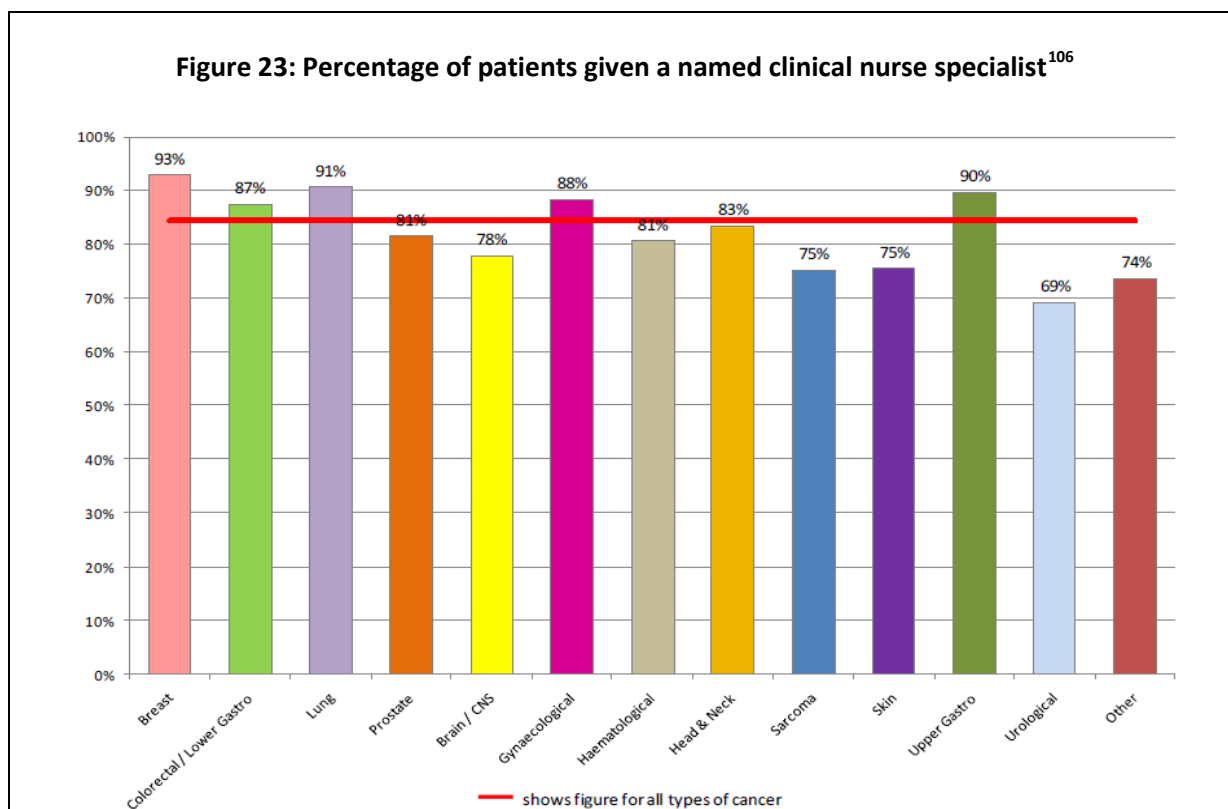
Despite these variations in access, there is a broad correlation between the number of lung cancer CNSs and incidence as shown in Figure 22.



**Figure 22: Correlation between number of lung clinical nurse specialists<sup>102</sup> and incidence of trachea, bronchus and lung cancer<sup>103</sup>, by cancer network**



The National Cancer Patient Experience Survey 2010 found that 91% of lung cancer patients who responded to the survey stated that they had been given a named clinical nurse specialist<sup>104</sup>. Only breast cancer patients reported a higher response in terms of access to a CNS (93%)<sup>105</sup>. When compared with the rates shown in Figure 23, this finding suggests that being given the name of a CNS does not necessarily translate into being seen by a CNS. This may be linked to the high caseload of lung cancer CNSs compared with CNSs for other types of cancer. Alternatively, this may further demonstrate that only the most healthy lung cancer patients were able to participate in the National Cancer Patient Experience Survey.



The National Lung Cancer Audit 2010 found that of patients seen by a lung CNS, 64.8% went on to receive treatment<sup>107</sup>. Out of those patients who did not see a CNS just 30.4% were given treatment<sup>108</sup>.

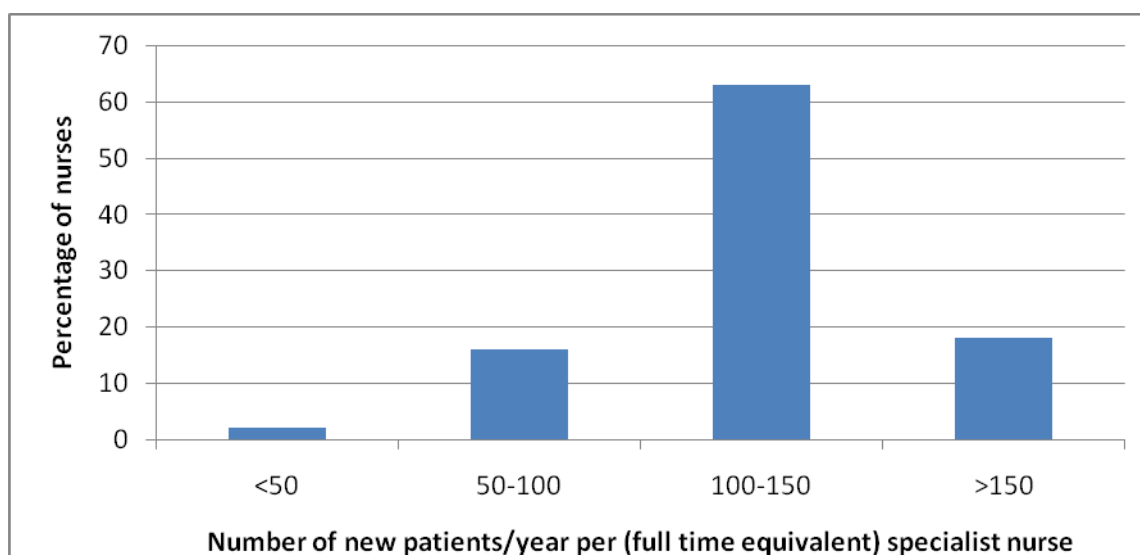
The percentage of people seen by a CNS varies significantly across cancer networks, from 13.6% (Kent and Medway Cancer Network) to 90.4% (Dorset Cancer Network). Three-quarters of lung cancer patients were seen by a CNS, while 43.7% had a CNS present at diagnosis<sup>109</sup>. There is more than a ten-fold variation between cancer networks in the percentage of people who have a lung CNS present at diagnosis. In Essex Cancer Network, 70.9% of people had a lung CNS present when they received their diagnosis. In Avon, Somerset and Wiltshire, the level was just 6.5%<sup>110</sup>.

**Lung cancer patients are more than twice as likely to receive active anti-cancer treatment if they are seen by a lung cancer nurse specialist.**

Interestingly, a number of cancer networks with a higher volume of patients with lung cancer actually scored relatively well on access to lung cancer CNS. This group included Essex, North of England, Peninsula, North London and Merseyside and Cheshire cancer networks<sup>111</sup>. This is a good example of a local response to clinical need as some areas must have identified their high incidence of lung cancer and responded by ensuring that there is sufficient CNS provision.

The NICE Clinical Guideline 121: *The diagnosis and treatment of lung cancer (update)* shows that the most common case load for a lung cancer nurse specialist is between 100-150 cases per year<sup>112</sup>. It is thought that once a CNS has a bigger case load than this they are unlikely to be able to give patients the time that they need to have a positive experience and to achieve the best outcomes possible.

**Figure 24: The variation in workload of new patients per full time equivalent specialist nurse (England only data)**<sup>113</sup>

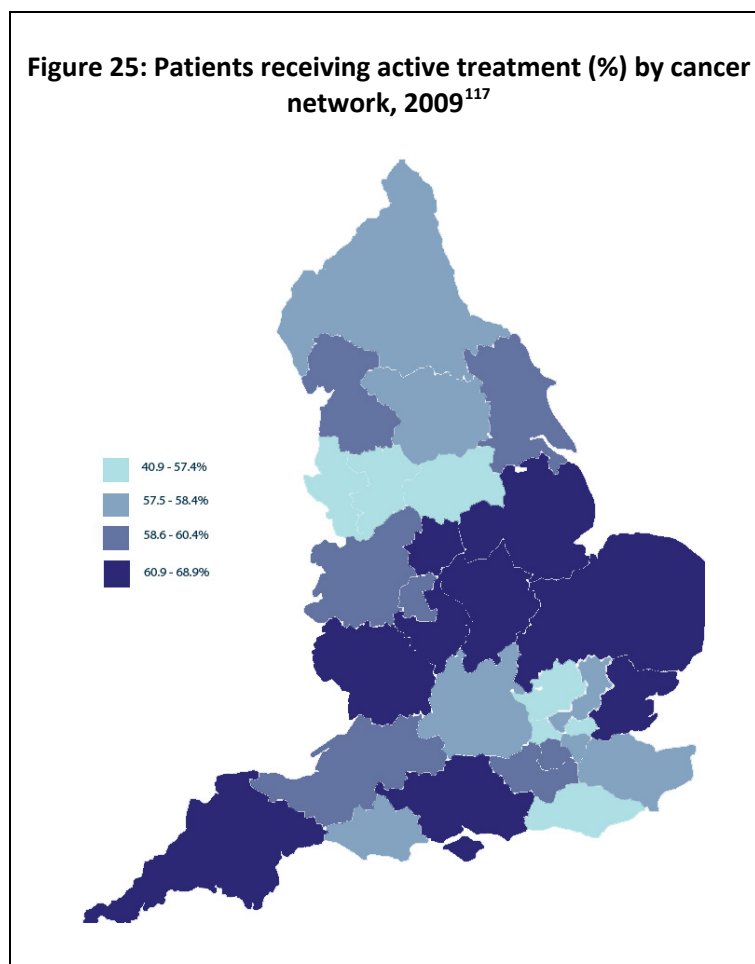


The National Lung Cancer Audit 2010 recommends that over 80% of lung cancer patients should be seen by a lung CNS<sup>114</sup>. 92 trusts out of a total of 156 in England are reported as failing this recommendation. The National Lung Cancer Audit also recommends that trusts should achieve an 80% rate for the proportion of patients who have a lung cancer CNS present at diagnosis. 134 trusts out of a total of 156 in England are failing to achieve this level<sup>115</sup>.

**We call on the government to ensure that all patients have equitable access to the best treatment and care, including access to specialist nurses at all times.**

## 8. Treatment

The National Lung Cancer Audit 2010 data show that there is variation across England in relation to the number of lung cancer patients receiving active treatment, as shown in Figure 25. Almost half of trusts in England (74 out of 156) currently have below-average active treatment rates<sup>116</sup>.

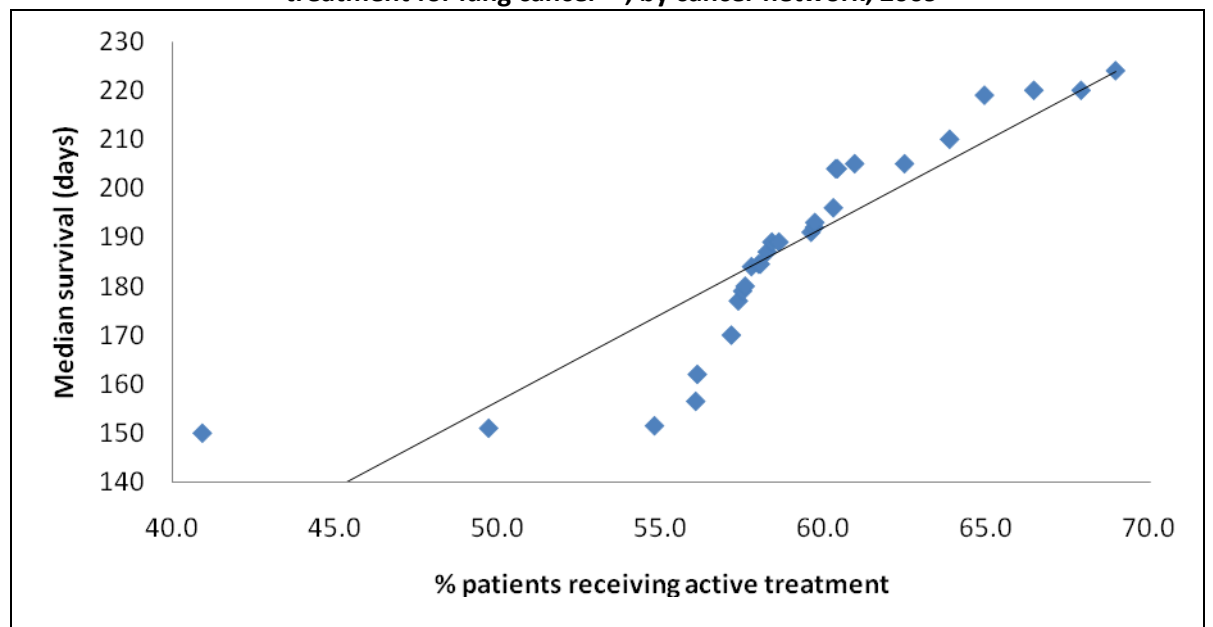


NB: Quartiles have been used to determine the ranges above

The highest scoring network on active treatment rates is Peninsula Cancer Network, where seven in ten patients receive active treatment, compared to only four in ten patients in Mount Vernon Cancer Network<sup>118</sup>.

There is a strong correlation between median survival and active treatment rates for lung cancer<sup>119, 120</sup>, as shown in Figure 26. This highlights the need to ensure that more lung cancer patients receive active cancer treatment, including surgery.

**Figure 26: Correlation between median survival<sup>121</sup> and percentage of patients receiving active treatment for lung cancer<sup>122</sup>, by cancer network, 2009**

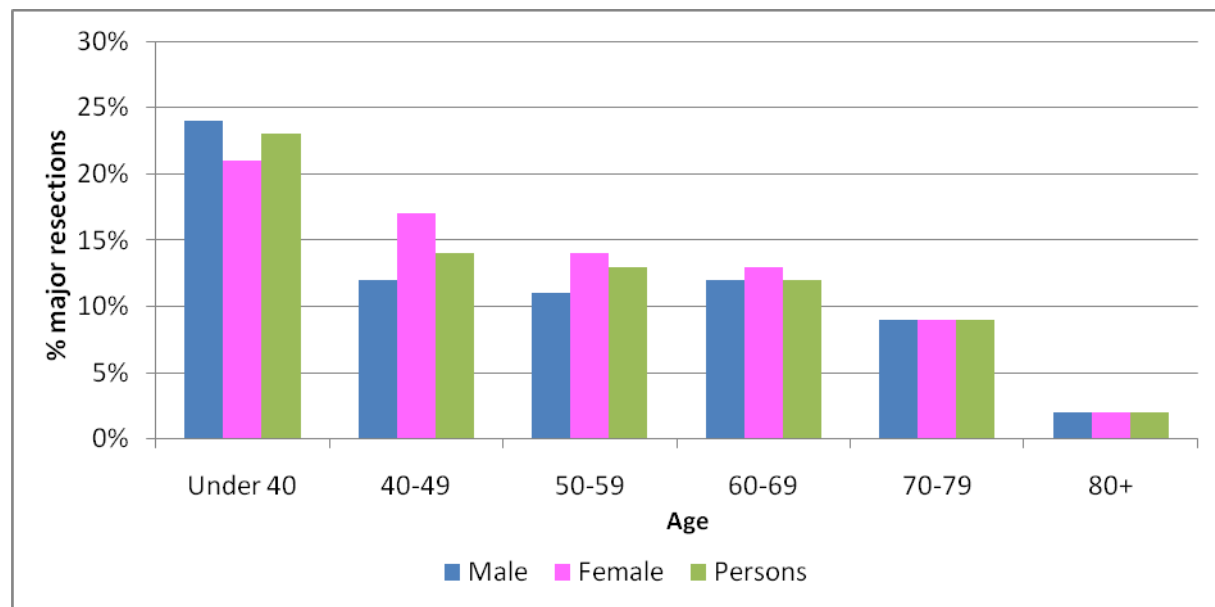


Reiterating the findings of the previous year, the National Lung Cancer Audit 2010 found that there is a four-fold variation in the rate of surgery for lung cancer patients across England<sup>123</sup>. This suggests there is scope to improve outcomes by increasing treatment rates in those parts of the country where they are low.

Surgery rates are at a relatively low level in all areas, with just 19.9% of lung cancer patients receiving surgery in the best-performing area, North East London Cancer Network, where a patient is more than twice as likely to receive cancer surgery as a patient in Sussex Cancer Network<sup>124</sup>.

There is substantial evidence that older patients are under-treated<sup>125</sup> and that they have poorer outcomes as a result<sup>126</sup>. Several studies suggest that differences in treatment partly explain poorer survival in older people with lung cancer<sup>127</sup>.

**Figure 28: NHS treated patients with a record of a major resection for lung cancer by sex and age, 2004-06, followed up to 2007<sup>128</sup>**

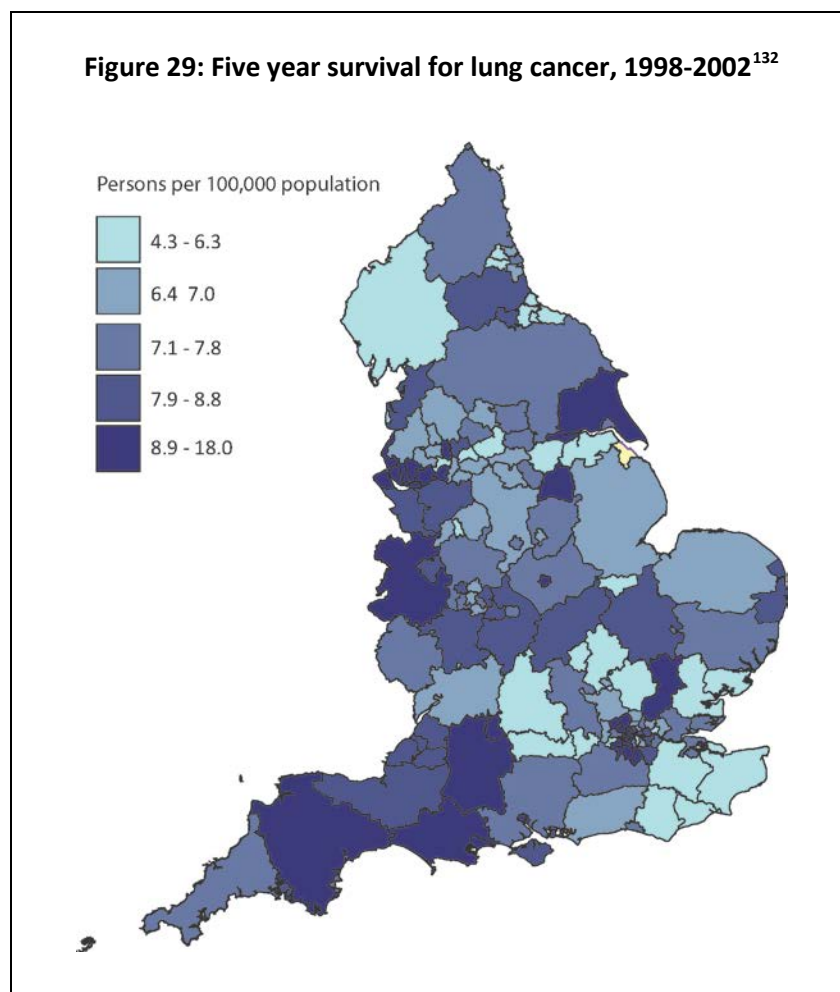


The percentage of patients with a record of a major resection is similar for males and females within each age band. However, there was a higher rate for females in the 40-49 age band compared to males<sup>129</sup>. There is a decrease in the percentage of patients with a record of a major resection across age groups. For patients aged 60-69, 12% of patients have a record of a major resection, compared to 2% of patients aged 80 and over<sup>130</sup>.

**We urge trusts and commissioners to scrutinise the results of the National Lung Cancer Audit 2010 to determine and act upon areas where improvements need to be made.**

## 9.Survival

Five year survival in cancer is considered to be an indication that a patient is going to survive a cancer diagnosis long-term. Five year survival rates for lung cancer are much more fragmented across England than for one year survival. In the latest period where data is available, the urban hubs of London and Manchester perform well, which may be as a result of high quality secondary and tertiary care centres in these areas<sup>131</sup>.



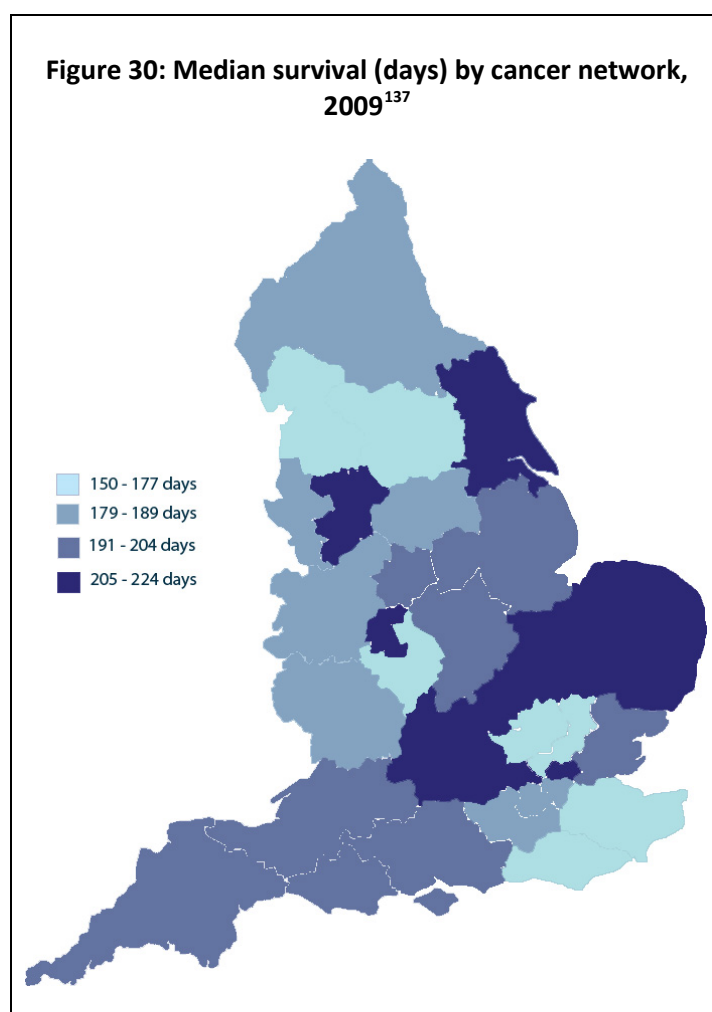
NB: Quintiles have been used to determine the ranges above

Dorset PCT was in the worst performing quintile for one year survival, but is in the top performing quintile for five year survival<sup>133</sup>. This may indicate that there is a problem with late diagnosis, but if a patient is diagnosed with an earlier stage of lung cancer then they achieve good outcomes. Kensington and Chelsea PCT has the highest five year survival rate of 18 persons per 100,000, whilst Peterborough PCT has the lowest five year survival rate of 4.3 persons per 100,000<sup>134</sup>.

**As with other data, there is a significant time lag in collecting, analysing and publishing information on five year survival. This makes it difficult to understand how survival patterns are**

changing. As part of the Government's information revolution we hope that data collection can be streamlined, making it as near to 'real-time' as possible.

The National Lung Cancer Audit collects information about survival, which is more up to date than that published by the Office of National Statistics. The 2010 Audit found that the median survival across cancer networks ranges from 150 days (Arden Cancer Network) to 224 days (Thames Valley Cancer Network)<sup>135</sup>. The average survival across all networks stands at 188.5 days, meaning that a lung cancer patient will survive on average for just over half a year post diagnosis<sup>136</sup>. This demonstrates what a poor prognosis lung cancer still has and how much more needs to be done to improve patient outcomes. Figure 30, below, shows that there are significant variations in lung cancer survival (days) across England.



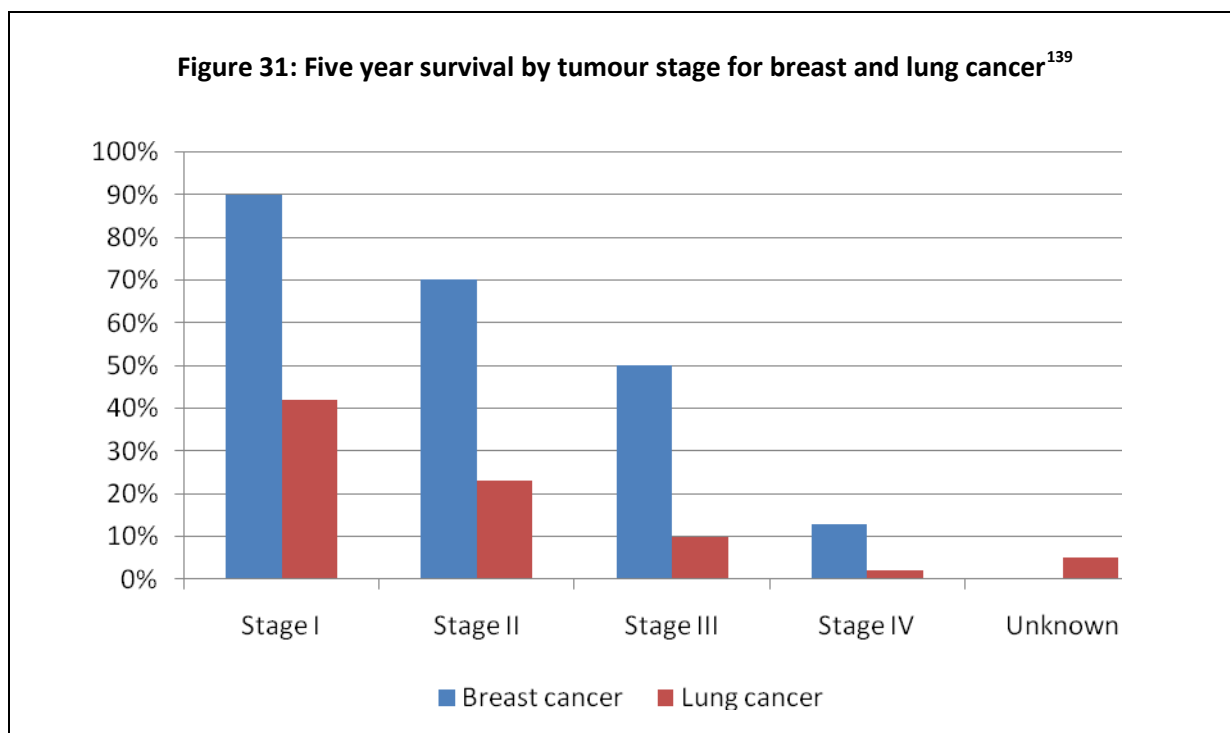
NB: Quartiles have been used to determine the ranges above

**Patients diagnosed with stage III breast cancer are more likely to survive five years post diagnosis than lung cancer patients diagnosed at stage I.**

These low levels of survival for lung cancer patients are further contextualised when information about five year survival by tumour stage is considered. We know that lung cancer has a worse prognosis than any of the other 'big-four' cancers and outcomes are also poor when compared to other rarer cancers. Looking at the five year survival by tumour stage shows that even if a lung cancer patient is diagnosed with stage I cancer they only have a



42% chance of surviving five years post diagnosis, compared to 90% of breast cancer patients. When lung cancer is diagnosed at stage IV, patients, on average, have a 2% likelihood of surviving five years post diagnosis compared to 13% for breast cancer patients<sup>138</sup>.



Regardless of the stage of a tumour at diagnosis, lung cancer patients have a much worse prognosis than breast cancer patients. Patients with breast cancer diagnosed with stage III breast cancer are more likely to survive five years post diagnosis than lung cancer patients diagnosed at stage I<sup>140</sup>.

**We welcome the Government’s drive to improve both one and five year survival for lung cancer through inclusion of these measures in the *The NHS Outcomes Framework 2011/12*<sup>141</sup>, as an improvement area in domain one “preventing people from dying prematurely”. We hope that this ongoing scrutiny of outcomes in lung cancer will lead to much needed improvements in outcomes for patients.**

## 10. Spending

In 2009-10 approximately £5.86 billion was spent on cancer in England. Of this £280 million (4.8%) was spent on lung cancer<sup>142</sup>.

Being able to access tumour-specific expenditure information is relatively new. This means that data may not be a truly accurate picture of how money is actually being spent on the ground. However, programme budgeting data is the most accurate spending data available and therefore provides an interesting snapshot of how money is being spent across the country.

**Figure 32: Programme budget spend on lung cancer, % change between 2008/09 and 2009/10<sup>143</sup>**

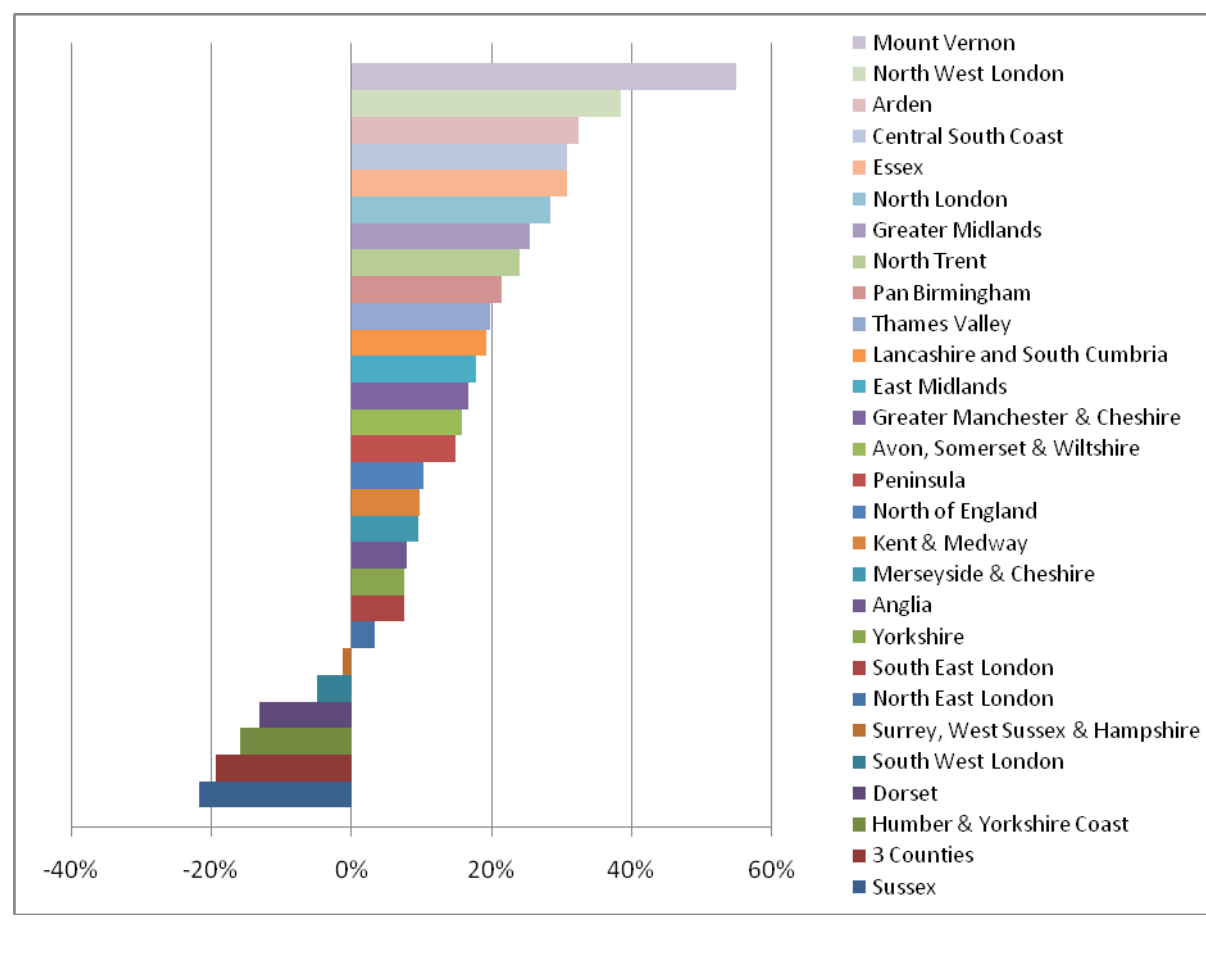
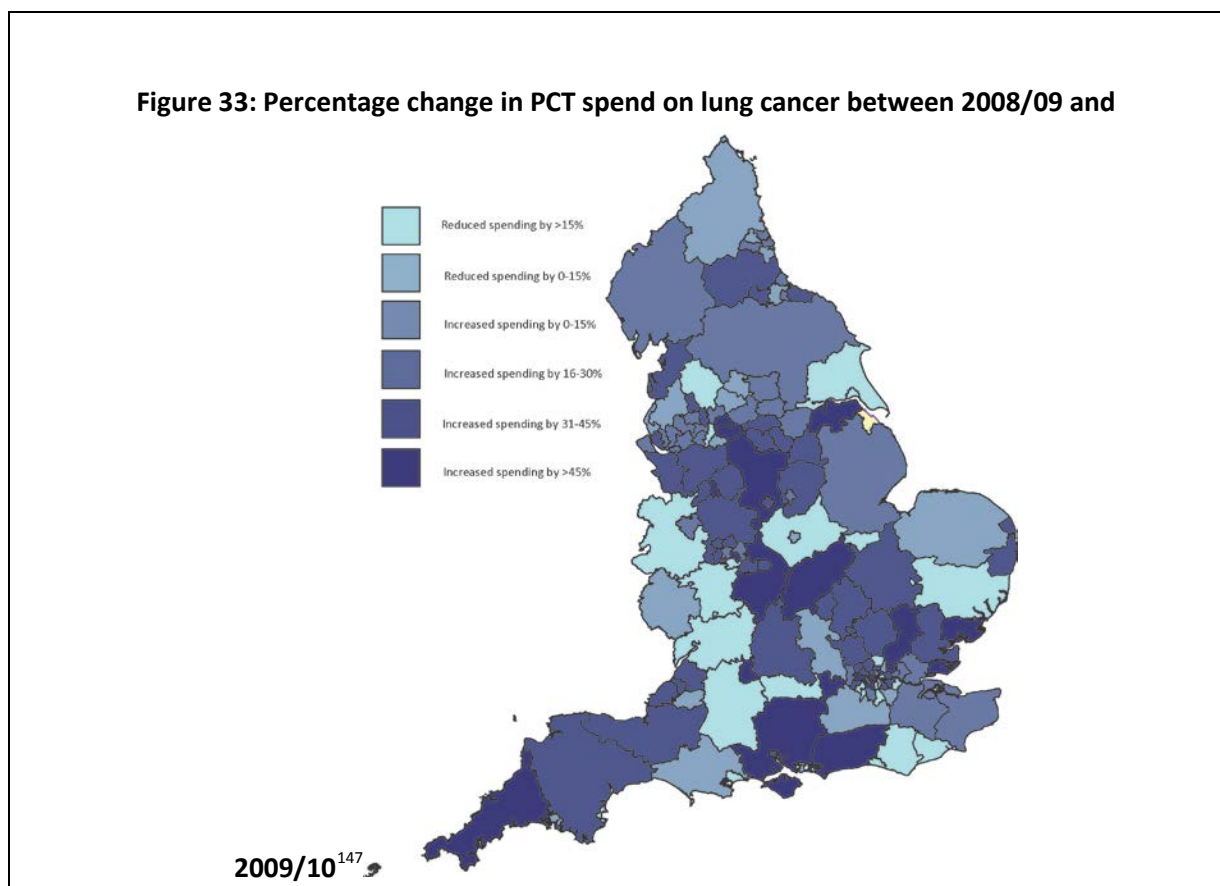


Figure 32, above, shows the percentage change in spending for lung cancer between 2008/09 and 2009/10 across cancer networks. This shows that although most cancer networks are spending more on lung cancer in 2009/10, six cancer networks (more than one fifth) spent less money on lung cancer in 2009/10 than they did in the previous financial year<sup>144</sup>. The extent of the variation is significant. For example, Sussex Cancer Network spent 22% less during 2009/10 than in the previous

year, whereas Mount Vernon Cancer Network spent 55% more when comparing the same time periods<sup>145</sup>.

There are a number of possible explanations for this, for example coding related to lung cancer may have improved in Mount Vernon Cancer Network or they may have been investing to improve services as they had the fifth lowest expenditure of all cancer networks during 2009/10<sup>146</sup>.

In order to understand the picture more clearly, Figure 33 shows how PCTs altered their levels of spending on lung cancer between 2008/09 and 2009/10.



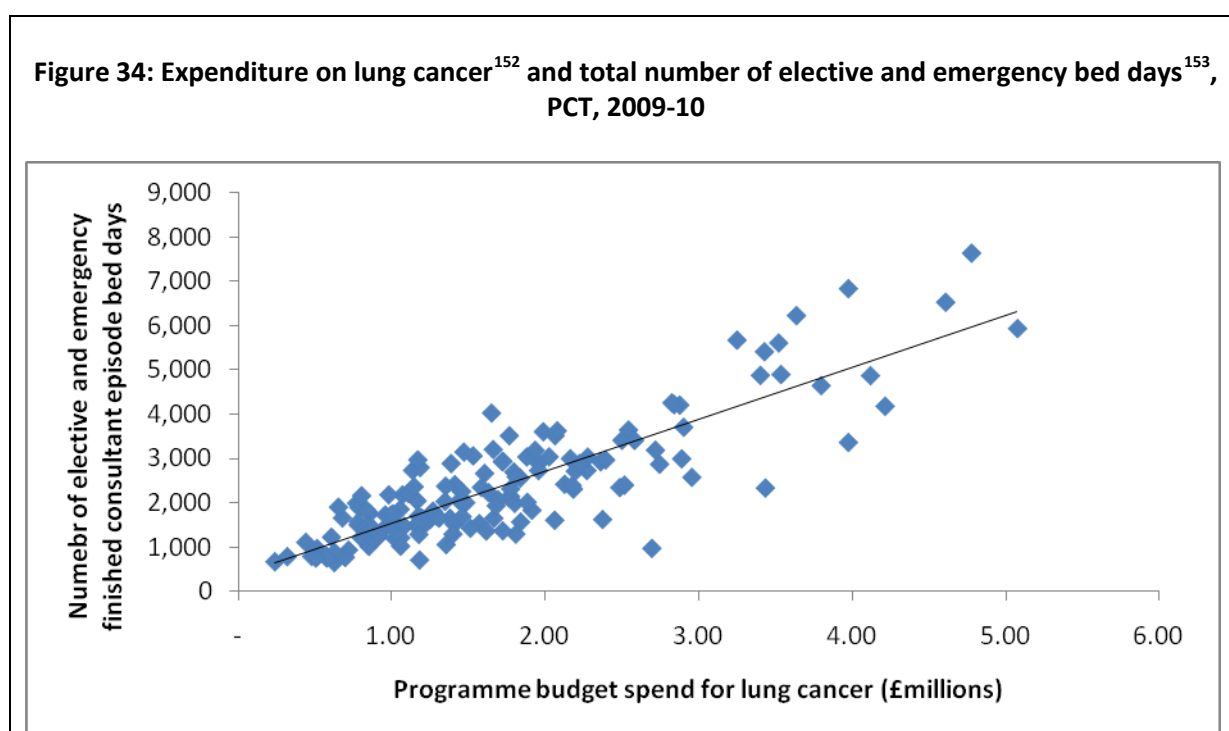
One third of PCTs reduced their spending over this period, and half of those that reduced their spending did so by more than 15%<sup>148</sup>. Berkshire West PCT had the most dramatic reduction at 40.5%<sup>149</sup>.

Of the two thirds that increased their spending on lung cancer, 26 PCTs did so by more than 45%, with four PCTs (Great Yarmouth and Waveney, North Staffordshire, Blackpool and Bury) more than doubling their budget over this period<sup>150</sup>.

Although there are significant limitations in comparing different data which cover different time periods, it is interesting that PCTs at both ends of the spectrum (Berkshire West and Blackpool) were in the lowest quintile for one year survival in 2006<sup>151</sup> and five year survival for 1998-2002. Bury PCT, meanwhile, was in the lowest quintile for one year survival but in the highest quintile for five-year survival.

The trends on changes in spending require further investigation at a local level. For those PCTs that have made dramatic changes to their spending on lung cancer, we recommend that local investigation should be undertaken to establish the reasons behind the change and whether any assessment has been made of how this has affected outcomes for people with lung cancer.

In order to understand overall expenditure on lung cancer, it is interesting to compare expenditure and inpatient bed days in order to further understand what drives expenditure across the country. This correlation is shown in Figure 34.



This graph demonstrates that there is a relatively strong correlation between overall PCT expenditure on lung cancer<sup>154</sup> and the number of elective and emergency bed days<sup>155</sup>. This suggests that if the number of bed days used in lung cancer could be reduced then it is likely that overall expenditure would also be reduced.

By using NHS reference costs 2009-10, it is estimated that the national average unit cost for emergency inpatient activity for lung cancer patients is £2,467.44<sup>156</sup>. This suggests that over £70 million was spent on this activity during 2009-10<sup>157</sup>. This represents 25% of the overall programme budget expenditure for lung cancer and is therefore significant. Although some of these episodes of care will be necessary, it would be significantly cheaper if these were managed through planned care rather than as an emergency admission as it is estimated that the national average unit cost for elective inpatient activity for lung cancer patients was £1,737.08 during 2009-10<sup>158</sup>.

**We believe that patients and carers should be given more support to self-manage their condition so that they know who to contact when assistance is needed and in order to avoid unnecessary emergency admissions. Additionally, patients should have a clearly defined care plan based on their individual needs which sets out reasons for admission to hospital.**

It is imperative that the government invests in lung cancer services, and that all patients have equitable access to the best treatment and care.

## 11. Conclusions

Despite recent advances, lung cancer continues to be the most common cause of cancer death in England, and survival in England continues to lag behind other comparable countries. The Roy Castle Lung Cancer Foundation is wholly committed to the defeat of this devastating disease.

This report has examined the data on lung cancer highlighting poor survival rates, variations and inequalities in treatment and patient experience. Although there have been some improvements in outcomes in recent decades, currently too few patients survive one year following a diagnosis of lung cancer, let alone five years.

We would like to see significant further improvements in survival and patient experience. We welcome the Government's commitment to bringing lung cancer survival in line with other comparable countries; and to improve both one and five year survival rates.

We also call for raising awareness of lung cancer signs and symptoms amongst GPs, pharmacists, stop-smoking professionals and the general public, leading to earlier diagnosis of lung cancer and wider access to curative treatment.

We believe that by universalising best practice, we can ensure that all patients have equitable access to the best treatment and care, including access to specialist nurses.

We hope that the findings and recommendations from this report will highlight the variations in lung cancer to policymakers, healthcare commissioners and health professionals to enable them to reduce variations and inequalities, and to significantly improve patient experience and outcomes.

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